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ABSTRACT

This compilation includes a variety of perspectives and resources on providing appropriate and effective programs and services for young children with autism and their families. It is designed for use by state-level early intervention and early childhood special education staff, local service providers, training and technical assistance providers, preservice and inservice educators, families, and others who are interested in the special needs of children with autism. The resources are organized into four sections. The first section provides an overview of general and descriptive information about autism, including definitions, etiology, characteristics, symptoms, diagnostic criteria, and accompanying disorders and conditions. Parent perspectives are also presented, as well as an update from the National Institutes of Health Autism Working Group regarding current and recommended research activities. The second section discusses intervention and education, which includes perspectives and considerations for early intervention and special education such as designing programs, guidance for examining and evaluating different treatments or interventions, service delivery implications and issues, and a parental perspective on print resources. The third section considers legal issues under the Individuals with Disabilities Education Act 1997, dispute resolution, court litigation, strategies for avoiding litigation and working with families, and mediation. The fourth section provides a glossary of terms. (CR)

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NECTAS Resource Collection on Autism Spectrum Disorders

Kathy T. Whaley & Evelyn Shaw,
Editors

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July 1999

CONNECTING PEOPLE & KNOWLEDGE
NECTAS
National Early Childhood
Technical Assistance System
Chapel Hill, North Carolina

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with

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Georgetown University Child Development Center
National Association of State Directors of Special Education (NASDSE)
ZERO TO THREE: National Center for Infants, Toddlers and Families

For more information about NECTAS, please contact the Coordinating Office at:

137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
(919) 962-2001 (voice)
962-8300 (TDD)
Fax: (919) 966-7463
E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/

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Additional copies of the *Resource Collection* are available at cost from NECTAS. A complete list of NECTAS resources is available at our Web site or upon request.

NECTAS is committed to making the information it disseminates fully accessible to all individuals. If you require any of this information in an alternate format, please contact the publications coordinator at the NECTAS Coordinating Office.

July 1999

Principal Investigator: Pascal Trohanis
Project Officer at OSEP: Peggy Cvach
Editors: Kathy T. Whaley, Siobhan Colgan, Evelyn Shaw, and Nicole Ament
Managing Editor: Nancy Guadagno
Publications Staff: Amy Ramirez

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Introduction

NECTAS has developed this *Resource Collection* as part of the technical assistance and dissemination activities of its National Forum on Autism Spectrum Disorders (ASD). NECTAS — with the concurrence of its funding agency, the Office of Special Education Programs (OSEP) of the U.S. Department of Education — is conducting a National Forum on policy and service system issues related to meeting the needs of young children with ASD and their families.

NECTAS defined a Forum as a series of problem-solving and information-gathering activities focused on an issue of national significance to the fields of early intervention and preschool special education. Using multiple strategies, activities, and events, we have incorporated the expertise and perspectives of state agency personnel, service providers, families, parent organizations, researchers, model program developers, health care professionals, university faculty, and training and technical assistance providers.

A preliminary version of this resource collection was developed for the participants of two NECTAS conferences held in 1997 as part the National Forum on ASD. These conferences — one in Denver, Colorado, and the second in Clearwater Beach, Florida — provided training and technical assistance for teams from 30 states and territories. As a result of the participants' positive feedback, NECTAS decided to update and revise the packet of materials provided to conference participants into a resource collection.

These materials, although not inclusive of the vast number of resources in the area of ASD, represent a variety of perspectives and resources for providing appropriate and effective programs and services for young children with autism and their families. The inclusion of any particular resource does not signify or imply endorsement by NECTAS or by its funding agency. This resource collection is designed for use by state-level early intervention and early childhood special education staff, local service providers, training and technical assistance providers, preservice and inservice educators, families and others who are interested in the special needs of children with ASD.

The resources in this collection are organized in the following sections:

- **Overview** — general and descriptive information about ASD including definitions, etiologies, characteristics, symptoms, diagnostic criteria and accompanying disorders and conditions. Parent perspectives are presented as well as an update from the National Institutes of Health Autism Working Group regarding current and recommended research activities.
- **Considerations for Intervention and Education** — perspectives and considerations for early intervention and special education such as designing programs, guidance for examining and evaluating different treatments or interventions, service delivery implications and issues, and a parental perspective on print resources.

- **Legal Issues Under IDEA** — elements of IDEA related to a free appropriate public education (FAPE) and dispute resolution. The relationship between litigation and specific methodologies is explored and a history of court decisions is provided. Strategies for avoiding litigation and working with families are described. Mediation as an alternative dispute resolution process mandated under IDEA is discussed and further illuminated through an accompanying case study.
- **Glossary of Terms** — an adaptation of a glossary of commonly used terms developed and maintained by the Autism Society of America.
- **National Contacts and Other References on ASD in Early Childhood** — contact information and program descriptions for agencies, organizations, and state or federally funded projects conducting research and/or providing information, support, training, and technical assistance on ASD for parents and professionals. Most of the listed contacts focus on ASD. Other national contacts are included that, while not focused on ASD, offer specific resources on ASD in early childhood.
- **OSEP-Funded Early Childhood Projects and Project Materials on ASD** — contact information for and descriptions of OSEP-funded early childhood demonstration and outreach projects that are focused on ASD, and descriptions of training materials, classroom curricula, and other resources on ASD that were developed by OSEP-funded early childhood projects.
- **Annotated Bibliography on ASD** — annotated references organized by the following topical headings: Overviews of Autism; Neurological, Biological and Genetic Influences; Assessment and Diagnosis; Educational Approaches; Family Training and Support; Individual and Family Accounts; and Books for Children.

We would like to acknowledge the following individuals who reviewed, edited, provided ideas, and suggested resources for either the previous or current version of the resource collection: Nicole Ament, Betsy Ayankoya, Carol Berman, Kim Brame, Siobhan Colgan, Terri Daly, Joicey Hurth, Sue Izeman, Lisa Napp, Laurie Sperry, Phil Strain, Pat Trohanis, Tina Vaughn, Heather Whiteford, Mark Wolery, and Martha Ziegler. We would also like to extend our sincere appreciation to our managing editor at NECTAS, Nancy Guadagno, for her technical skill and personal support for this project.

Kathy Whaley and Evelyn Shaw
Editors
July 1999

Overview

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FS20, January 1998

NICHCY

BRIEFING PAPER

Pervasive Developmental Disorders

By Luke Y. Tsai, M.D.

Every year the National Information Center for Children and Youth with Disabilities (NICHCY) receives thousands of requests for information about the diagnosis, educational programming, and special needs of children and youth with Pervasive Developmental Disorders (PDD). Over the past few years, PDD has become a subject of increased attention among parents, professionals, and policymakers across the country.

NICHCY developed this *Briefing Paper* in response to the growing concern about, and interest in, this disability. This publication is designed to answer some of the most commonly asked questions regarding PDD and to provide concerned individuals with other resources for information and support.

Introduction

The term Pervasive Developmental Disorders was first used in the 1980s to describe a class of disorders. This class of disorders has in common the following characteristics: impairments in social interaction, imaginative activity, verbal and nonverbal communication skills, and a limited number of interests and activities that tend to be repetitive.

The manual used by physicians and mental health professionals as a guide to diagnosing disorders is the *Diagnostic and*

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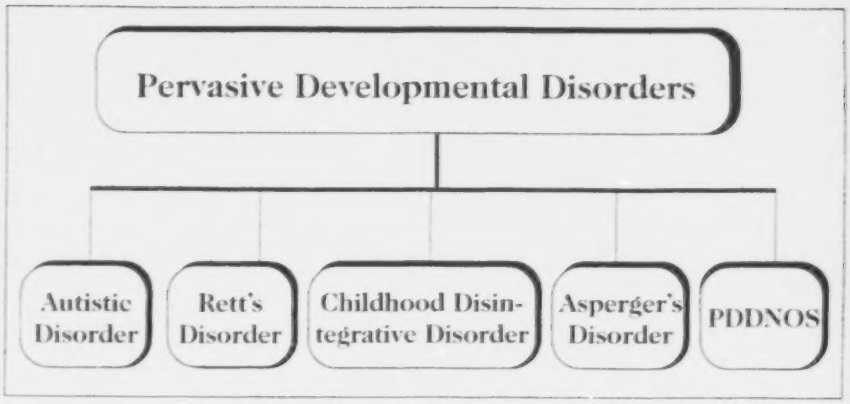
Statistical Manual of Mental Disorders (DSM). The DSM was last revised in 1994. In this latest revision, known as the DSM-IV, five disorders are identified under the category of Pervasive Developmental Disorders (see chart at right): (1) Autistic Disorder, (2) Rett's Disorder, (3) Childhood Disintegrative Disorder, (4) Asperger's Disorder, and (5) Pervasive Developmental Disorder Not Otherwise Specified, or PDDNOS.



Many of the questions parents and education professionals ask NICHCY have to do with children who have been diagnosed with "PDD." Doctors are divided on the use of the term PDD. Many professionals use the term PDD as a short way of saying PDDNOS. Some doctors, however, are hesitant to diagnose very young children with a specific type of PDD, such as Autistic Disorder, and therefore only use the general category label of PDD. This approach contributes to the confusion about the term, because the term PDD actually refers to a *category* of disorders and is not a diagnostic label. The appropriate diagnostic label to be used is PDDNOS—Pervasive Developmental Disorder Not Otherwise Specified—not PDD (the umbrella category under which PDDNOS is found).

Accordingly, this *Briefing Paper* will use the term PDD to refer to the overall category of Pervasive Developmental Disorders and the term PDDNOS to refer to the specific disorder, Pervasive Developmental Disorder Not Otherwise Specified. The majority of this *Briefing Paper* will focus on PDDNOS.

All of the disorders that fall under the category of PDD share, to some extent, similar characteristics. To understand how the disorders differ and how they are alike, it's useful to look at the definition of each disorder. Therefore, before we begin our discussion of PDDNOS, let us look first at the definition of the general category PDD and its specific disorders.

Definition of the PDD Category and its Five Specific Disorders

All types of PDD are neurological disorders that are usually evident by age 3. In general, children who have a type of PDD have difficulty in talking, playing with other children, and relating to others, including their family.

According to the definition set forth in the DSM-IV (American Psychiatric Association, 1994), Pervasive Developmental Disorders are characterized by severe and pervasive impairment in several areas of development:

- social interaction skills;
- communication skills; or
- the presence of sterotyped behavior, interests, and activities. (p. 65)

The Five Types of PDD

(1) Autistic Disorder. Autistic Disorder, sometimes referred to as *early infantile autism* or *childhood autism*, is four times more common in boys than in girls. Children with Autistic Disorder have a moderate to severe range of communication, socialization, and behavior problems. Many children with autism also have mental retardation. The DSM-IV criteria by which Autistic Disorder is diagnosed are presented on page 3.

(2) Rett's Disorder. Rett's Disorder, also known as Rett Syndrome, is diagnosed primarily in females. In children with Rett's Disorder, development proceeds in an apparently normal fashion over the first 6 to 18 months at which point parents notice a change in their child's behavior and some regression or loss of abilities, especially in gross motor skills such as walking and moving. This is followed by an obvious loss in abilities such as speech, reasoning, and hand use. The repetition of certain meaningless gestures or movements is an important clue to diagnosing Rett's Disorder; these gestures typically consist of constant hand-wringing or hand-washing (Moeschler, Gibbs, & Graham 1990). The diagnostic criteria for Rett's Disorder as set forth in the DSM-IV appear in the second box on page 3.

(3) Childhood Disintegrative Disorder. Childhood Disintegrative Disorder, an extremely rare disorder, is a clearly apparent regression in multiple areas of functioning (such as the ability to move, bladder and bowel control, and social and

Diagnostic Criteria for Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(b) failure to develop peer relationships appropriate to developmental level

(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

(c) stereotyped and repetitive use of language or idiosyncratic language

(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(b) apparently inflexible adherence to specific, nonfunctional routines or rituals

(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. (APA, 1994, pp. 70-71)

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Diagnostic Criteria for Rett's Disorder

A. All of the following:

(1) apparently normal prenatal and perinatal development

(2) apparently normal psychomotor development through the first 5 months after birth

(3) normal head circumference at birth

B. Onset of all of the following after the period of normal development

(1) deceleration of head growth between ages 5 and 48 months

(2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)

(3) loss of social engagement early in the course (although often social interaction develops later)

(4) appearance of poorly coordinated gait or trunk movements

(5) severely impaired expressive and receptive language development with severe psychomotor retardation. (APA, 1994, pp. 72-73)

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language skills) following a period of at least 2 years of apparently normal development. By definition, Childhood Disintegrative Disorder can *only* be diagnosed if the symptoms are preceded by *at least* 2 years of normal development and the onset of decline is prior to age 10 (American Psychiatric Association, 1994). DSM-IV criteria are presented below.

(4) Asperger's Disorder. Asperger's Disorder, also referred to as Asperger's or Asperger's Syndrome, is a developmental disorder characterized by a lack of social skills; difficulty with social relationships; poor coordination and poor concentration; and a restricted range of interests, but normal intelligence and adequate language skills in the areas of vocabulary and grammar. Asperger's Disorder appears to have a somewhat later onset than Autistic Disorder, or at least is recognized later. An individual with Asperger's Disorder does not possess a significant delay in language development; however, he or she may have difficulty understanding the subtleties used in conversation, such as irony and humor. Also, while many individuals with autism have mental retardation, a person with Asperger's possesses an average to above average intelligence (Autism Society of America, 1995). Asperger's is sometimes incorrectly referred to as "high-functioning autism." The diagnostic criteria for Asperger's Disorder as set forth in the DSM-IV are presented in the box on page 5.

(5) Pervasive Developmental Disorder Not Otherwise Specified. Children with PDDNOS either (a) do not fully meet the criteria of symptoms clinicians use to diagnose any of the four specific types of PDD above, and/or (b) do not have the *degree* of impairment described in any of the above four PDD specific types.

According to the DSM-IV, this category should be used "when there is a severe and pervasive impairment in the development of social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder" (American Psychiatric Association, 1994, pp. 77-78).

Diagnostic Criteria for Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
(1) expressive or receptive language
(2) social skills or adaptive behavior
(3) bowel or bladder control
(4) play
(5) motor skills

C. Abnormalities of functioning in at least two of the following areas:
(1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
(2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
(3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms

D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia. (APA, 1994, pp. 74-75)

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The Confusion of Diagnostic Labels

The intent behind the DSM-IV is that the diagnostic criteria not be used as a checklist but, rather, as guidelines for diagnosing pervasive developmental disorders. There are no clearly established guidelines for measuring the severity of a person's symptoms. Therefore, the line between autism and PDDNOS is blurry (Boyle, 1995).

As discussed earlier, there is still some disagreement among professionals concerning the PDDNOS label. Some professionals consider "Autistic Disorder" appropriate only for those who show extreme symptoms in every one of several developmental areas related to autism. Other professionals are more comfortable with the term Autistic Disorder and use it to cover a broad range of symptoms connected with

Diagnostic Criteria for Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(2) failure to develop peer relationships appropriate to developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

(4) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(2) apparently inflexible adherence to specific, nonfunctional routines or rituals

(3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

(4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g., single word used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder, or Schizophrenia. (APA, 1994, p. 77)

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language and social dysfunction. Therefore, an individual may be diagnosed by one practitioner as having Autistic Disorder and by another practitioner as having PDDNOS (or PDD, if the practitioner is abbreviating for PDDNOS).

Generally, an individual is diagnosed as having PDDNOS if he or she has some behaviors that are seen in autism but does not meet the full DSM-IV criteria for having Autistic Disorder. Despite the DSM-IV concept of Autistic Disorder and PDDNOS being two distinct types of PDD, there is clinical evidence suggesting that Autistic Disorder and PDDNOS are on a continuum (i.e., an individual with Autistic Disorder can improve and be rediagnosed as having PDDNOS, or a young child can begin with PDDNOS, develop more autistic features, and be rediagnosed as having Autistic Disorder).

To add to the list of labels that parents, teachers, and others may encounter, a new classification system was recently developed by ZERO TO THREE: National Center for Infants, Toddlers, and Families (1994). Under this system, called the *Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood*, the term Multisystem Developmental Disorder, or MSDD, is used to describe pervasive developmental disorders.

However, amidst all this confusion, it is very important to remember that, regardless of whether a child's diagnostic label is autism, PDDNOS, or MSDD, his or her treatment is similar.

The Cause of PDDNOS

Both behavioral and biological studies have generated sufficient evidence to suggest that PDDNOS is caused by a neurological abnormality—problems with the nervous system. However, no specific cause or causes have been identified.

While studies have found various nervous-system problems, no single problem has been consistently found, and exact causes are far from clear. This may be due to the current approach of defining PDDNOS based on behaviors (as opposed to, say, genetic testing). Hence, it is possible that PDDNOS is the result of several different conditions. If this is the case, it is

anticipated that future studies will identify a range of causes.

The Symptoms and Signs of PDDNOS

Generally, children are 3 to 4 years old before they exhibit enough symptoms for parents to seek a diagnosis. There is no set pattern of symptoms and signs in children with PDDNOS. It is important to realize that a very wide range of diversity is seen in children with PDDNOS. All the items of behavior described in this section are common in these children, but a single child *seldom* shows all the features at one time. In other words, all children with PDDNOS do not have the same degree or intensity of the disorder. PDDNOS can be mild, with the child exhibiting a few symptoms while in the school or neighborhood environment. Other children may have a more severe form of PDDNOS and have difficulties in all areas of their lives. Because of the possibility that PDDNOS and Autistic Disorder are on a continuum, many clinical features described in the following section are very similar to those being described in the literature for Autistic Disorder.

PDDNOS is a spectrum disorder. It can be mild, with the child exhibiting a few symptoms while in the school or neighborhood environment. Other children may have a more severe form of PDDNOS and have difficulties in all areas of their lives.

Deficits in Social Behavior

Some infants with PDDNOS tend to avoid eye contact and demonstrate little interest in the human voice. They do not usually put up their arms to be picked up in the way that typical children do. They may seem indifferent to affection and seldom show facial responsiveness. As a result, parents often think the child is deaf. In children with fewer delays, lack of social responsiveness may not be obvious until well into the second or third year of life.

In early childhood, children with PDDNOS may continue to show a lack of eye contact, but they may enjoy a tickle or may passively accept physical contact. They do not develop typical attachment behavior, and there may seem to be a failure to bond. Generally, they do not follow their parents about the house. The majority do not show normal separation or stranger anxiety. These children may approach a stranger almost as readily as they do their parents. Many such children show a lack of interest in being with or playing with other children. They may even actively avoid other children.

In middle childhood, such children may develop a greater awareness or attachment to parents and other familiar adults. However, social difficulties continue. They still have problems with group games and forming peer relationships. Some of the children with less severe PDDNOS may become involved in other children's games.

As these children grow older, they may become affectionate and friendly with their parents and siblings. However, they still have difficulty understanding the complexity of social relationships. Some individuals with less severe impairments may have a desire for friendships. But a lack of response to other people's interests and emotions, as well as a lack of understanding of humor, often results in these youngsters saying or doing things that can slow the development of friendships.

Impairment in Nonverbal Communication

In early childhood, children with PDDNOS may develop the concrete gesture of pulling adults by the hand to the object that is wanted. They often do this without the typical accompanying facial expression. They seldom nod or shake their heads to substitute for or to accompany speech. Children with PDDNOS generally do not participate in games that involve imitation. They are less likely than typical children to copy their parents' activity.

In middle and late childhood, such children may not frequently use gestures, even when they understand other people's gestures fairly well. Some children do develop imitative play, but this tends to be repetitive.

Generally, children with PDDNOS are able to show joy, fear, or anger, but they may only show the extreme of emotions. They often do not use facial expressions that ordinarily show subtle emotion.

Impairment in Understanding Speech

Comprehension of speech in children with PDDNOS is impaired to varying degrees, depending on where the child is within the wide spectrum of PDDNOS. Individuals with PDDNOS who also have mental retardation may never develop more than a limited understanding of speech. Children who have less severe impairments may follow simple instructions if given in an immediate context or with the

aid of gestures (e.g., telling the child to "put your glass on the counter," while pointing to the counter). When impairment is mild, only the comprehension of subtle or abstract meanings may be affected. Humor, sarcasm, and common sayings (e.g., "it's raining cats and dogs") can be confusing for individuals with the most mild PDDNOS.

Impairment in Speech Development

Many infants with PDDNOS do not babble, or may begin to babble in their first year but then stop. When the child develops speech, he or she often exhibits abnormalities. Echolalia (seemingly meaningless repetition of words or phrases) may be the only kind of speech some children acquire. Though echolalic speech might be produced quite accurately, the child may have limited comprehension of the meaning. In the past, it was thought that echolalia had no real function. More recent studies have found that echolalia can serve several functions, such as self-stimulation (when a child says words or phrases repeatedly without a communicative purpose—just because it feels good); as a step between a child being nonverbal and verbal; or as a way to communicate (Prizant & Rydell, 1993). Other children develop the appropriate use of phrases copied from others. This is often accompanied by pronoun reversal in the early stages of language development. For instance, when the child is asked "How are you?" he or she may answer "You are fine."

The actual production of speech may be impaired. The child's speech may be like that of a robot, characterized by a monotonous, flat delivery with little change in pitch, change of emphasis, or emotional expression.

Problems of pronunciation are common in young children with PDDNOS, but these often diminish as the child gets older. There may be a striking contrast between clearly enunciated echolalic speech and poorly pronounced spontaneous speech. Some children have a chanting or singsong speech, with odd prolongation of sounds, syllables, and words. A question-like intonation may be used for statements. Odd breathing rhythms may produce staccato speech in some children.

Abnormal grammar is frequently present in the spontaneous speech of verbal children with PDDNOS. As a result:

- phrases may be telegraphic (brief and monotone) and distorted;
- words of similar sound or related meaning may be muddled;
- some objects may be labeled by their use;
- new words may be coined; and
- prepositions, conjunctions, and pronouns may be dropped from phrases or used incorrectly.

When children with PDDNOS do develop functional speech, they may not use it in ordinary ways. Such children tend to rely on repetitive phrases. Their speech does not usually convey imagination, abstraction, or subtle emotion. They generally have difficulty talking about anything outside of the immediate context. They may talk excessively about their special interests, and they may talk about the same pieces of information whenever the same subject is raised. The most able persons can exchange concrete pieces of information that interest them, but once the conversation departs from this level, they can become lost and may withdraw from social contact. Ordinary to-and-fro conversational chatter is lacking. Thus, they give the impression of talking "at" someone, rather than "with" someone.

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Unusual Patterns of Behavior

The unusual responses of children with PDDNOS to the environment take several forms.

Resistance to change. Many children are upset by changes in the familiar environment. Even a minor change of everyday routine may lead to tantrums. Some children line up toys or objects and become very distressed if these are disturbed. Efforts to teach new activities may be resisted.

Ritualistic or compulsive behaviors. Ritualistic or compulsive behaviors usually involve rigid routines (e.g., insistence on eating particular foods) or repetitive acts, such as hand flapping or finger mannerisms (e.g., twisting, flicking movements of hands and fingers carried out near the face). Some children develop preoccupations; they may spend a great deal of time memorizing weather information, state capitals, or birth dates of family members.

Abnormal attachments and behaviors. Some children develop intense attachments to odd objects, such as pipe cleaners, batteries, or film

Beginning the Search for Information

Sam was an active and busy child. But his parents were worried about him. Compared with the other 3-year-olds they knew, Sam was different—he wasn't talking and he didn't seem to want or try to play with his sister. At day care Sam wouldn't join in any activities with the other kids, but he really enjoyed playing with water. He would splash and play at the sink for hours, with a big smile on his face. After about a year of expressing concern to their pediatrician, Sam's parents finally obtained a referral to a developmental psychologist who diagnosed Sam as having PDDNOS. The pediatrician also suggested that they get the school to test Sam. The school tested him and said he had autism. No one seemed to know anything about PDDNOS, and although Sam's parents had heard of autism, they didn't know much about it. They began their search for information on what PDDNOS was and what autism was.

canisters. Some children may have a preoccupation with certain features of favored objects, such as their texture, taste, smell, or shape.

Unusual responses to sensory experiences. Many children may seem underresponsive or overresponsive to sensory stimuli. Thus, they may be suspected of being deaf or visually impaired. It is common for such young children to be referred for hearing and vision tests. Some children avoid gentle physical contact, yet react with pleasure to rough-and-tumble games. Some children carry food preferences to extremes, with favored foods eaten to excess. Some children limit their diet to a small selection, while others are hearty eaters who do not seem to know when they are full.

Disturbance of Movement

The typical motor milestones (e.g., throwing, catching, kicking) may be delayed but are often within the normal range. Young children with PDDNOS usually have difficulty with imitation skills, such as clapping hands. Many such children are very overactive, yet tend to become less overactive in adolescence. Children with PDDNOS may exhibit characteristics such as grimacing, hand flapping or twisting, toe walking, lunging, jumping, darting or pacing, body rocking and swaying, or head rolling or banging. In some cases the behaviors appear only from time to time; in other cases they are present continuously.

Intelligence and Cognitive Deficits

Generally, children with PDDNOS do very well on tests requiring manipulative or visual skills or immediate memory, while they do poorly on tasks demanding symbolic or abstract thought and sequential logic. The process of learning and thinking in these children is impaired, most particularly in the capacity for imitation, comprehension of spoken words and gestures, flexibility, inventiveness, learning and applying rules, and using acquired information. Yet, a small number of children with PDDNOS show excellent rote memories and special skills in music, mechanics, mathematics, and reading.

Because many children with PDDNOS are either without functional speech or otherwise untestable, some people question the validity of testing their intelligence. Moreover, it has been observed that a number of these children show major improvements in other developmental areas during the follow-up period without a change in their tested IQ. Follow-up studies have also shown that retardation present at the time of initial diagnosis tends to persist. Those children with a low IQ show more severely impaired social development. They are more likely to display unusual social responses, such as touching or smelling people, ritualistic behavior, or self-injury.

Associated Features

The emotional expression of some children with PDDNOS may be flattened, excessive, or inappropriate to the situation. For no obvious reason, they may scream or sob inconsolably one time, yet giggle and laugh hysterically another time. Real dangers, such as moving vehicles or heights, may be ignored, yet the same child might seem frightened of a harmless object, such as a particular stuffed animal.

Diagnosing PDDNOS

The DSM-IV suggests that the diagnostic label of PDDNOS be used when there is a severe and pervasive impairment in the development of reciprocal social interaction, verbal and nonverbal communication skills, or the development of seemingly meaningless repetitive behavior, interests, and activities, but when the criteria are not completely met for a specific disorder within the category PDD (e.g., Autistic Disorder, Rett's Disorder, Asperger's Disorder). However, the DSM-IV framework has not offered specific techniques or criteria for diagnosing PDDNOS.

No Specific Test Available

Currently, no objective biological test, such as a blood test or an X-ray examination, can confirm a child's PDDNOS diagnosis. Diagnosing PDDNOS is complicated and much like putting together a

jigsaw puzzle that does not have a clear border and picture. Therefore, it is reasonable to say that, when a PDDNOS diagnosis is made, it reflects the clinician's best guess. Obtaining an accurate diagnosis requires an assessment conducted by a well-trained professional who specializes in developmental disorders, usually a child psychiatrist, developmental pediatrician, pediatric neurologist, developmental pediatrician, child psychologist, developmental psychologist, or neuropsychologist.

PDDNOS Assessment

The purpose of PDDNOS assessment is twofold: to gather information to formulate an accurate diagnosis and to provide information that will form the basis of an appropriate intervention plan for the individual child and family. Assessment of PDDNOS usually includes the following elements:

Medical assessment. The medical evaluation should include a thorough birth, developmental, medical, and family history, and a full physical and neurological examination. Not all children with PDDNOS require laboratory tests such as a chromosome study, including a test for Fragile X, an EEG (which measures the brain's electrical activity), or a brain scan such as MRI (an X-ray that gives a picture of the brain's anatomy). The primary care physician determines if these are needed. Although the cause of PDDNOS is generally unknown, the physician may discuss some medical conditions that do not cause PDDNOS but tend to be found in such children—for example, seizure disorder. Associated conditions can cause or worsen a child's problems.

Interviews with the parents, child, and child's teacher. A child with PDDNOS may exhibit different abilities and behaviors in different settings or situations. Parents and teachers can provide information about behaviors not observed during the formal testing sessions.

Behavior rating scales. Checklists of possible problems should be completed by parents or caretakers familiar with the child. Many diagnosticians use the checklist for autism. However, no scale has yet been developed *specifically* to determine the diagnosis of PDDNOS.

Direct behavioral observations. The child's behavior is recorded as it happens, and assessment results are often graphed to aid interpretation. This type of assessment can be carried out either in an artificial situation (e.g., a child taking an intelligence test) or in a natural situation (e.g., a child's home or classroom).

Psychological assessment. The psychologist uses standardized instruments to evaluate the child's cognitive, social, emotional, behavioral, and adaptive functioning. Parents learn in which areas of development their child exhibits delays.

Educational assessment. Both formal assessment (such as the use of standardized tests) and informal assessment (such as direct observation and interviewing the parents) should be used to evaluate the child on the following points:

- preacademic skills (e.g., shape and letter naming),
- academic skills (e.g., reading and arithmetic),
- daily living skills (e.g., toileting, dressing, eating), and
- learning style and problem-solving approaches.

Communication assessment. Formal testing, observational assessment, and interviewing the child's parents are all useful strategies for assessing communication skills. It is important to assess a range of communication skills, including the child's interest in communication, why (for what purpose) the child communicates, the content and context of the communication, how the child communicates (including facial expression, posture, gestures, etc.), and how well the child understands when others communicate with him or her. Assessment results should be used when designing a communication program for the child. This may incorporate one or more alternative forms to spoken communication, such as sign language and/or using a communication board (i.e., pointing to pictures to express oneself).

Occupational assessment. An occupational therapist may evaluate the child to determine the nature of his or her sensory integrative functioning: how the child's different senses—hearing, sight, taste, smell, touch—work together. Standardized tools are used to assess fine motor skills (such as using fingers to pick up small objects), gross motor skills (such as running and jumping), whether the child is right or left handed, and various visual skills (such as depth perception).

Evaluation summary. The professional evaluating a child will use all the information collected through these varying techniques to decide whether that child has a disability that falls under the category of PDD. Assessment and evaluation can be done through the child's local public school or a private practitioner.

Special Education and PDDNOS

By law, schools must make special services available to eligible children with disabilities. These services are called *special education and related services* (discussed more below). The law that requires this is the Individuals with Disabilities Education Act, or IDEA. Under the IDEA, school-aged children who are thought to have a disability must be evaluated by the public schools at

no cost to parents. Based on the evaluation, a determination is made as to their eligibility for services.

IDEA defines categories of disability under which a child is considered eligible for services. These categories are: autism, deaf-blindness, hearing impairments including deafness, mental retardation, other health impairments, orthopedic impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, visual impairments including blindness, or multiple disabilities. If permitted by the state and the local educational agency, a school may also provide services to a student, from age 3 through age 9, under the separate category of "developmental delay." Parents should check with their state department of special education to find out what guidelines their state uses.

It's important to realize that a child may have a disability and still not be eligible for special education and related services. For a child to be determined to be eligible, the child's disability must adversely affect his or her educational performance.

Special education is instruction that is specially designed to meet a child's unique educational needs. Related services can include a range of services that are provided to help the student benefit from his or her special education. Related services include (but are not limited to) such services as occupational therapy, speech therapy, or physical therapy. Both special education and related services must be provided at no cost to the parents; both can be extremely beneficial for children with PDDNOS.

Services to very young children are also covered under the IDEA. Through the Program for Infants and Toddlers with Disabilities, states make *early intervention services* available to eligible infants and toddlers (birth through two years). Not all services are free; some may be provided on a sliding-scale basis (in other words, according to the parents' ability to pay).

Early intervention services are designed to meet the developmental needs of the infant or toddler in areas such as their physical development, cognitive development, communication development, social or emotional development, or adaptive development. Services include (but are not limited to) such services as: family training and home visits, special instruction, speech-language pathology, vision services, and occupational therapy. To the maximum extent appropriate, early intervention services are to be provided in natural environments, including the home and community settings in which children without disabilities participate.

The IFSP and the IEP

The majority of school-aged children with PDDNOS will need some special education services, just as those who are younger will need early intervention services. If a school-aged child is found eligible for services, the parents and the school will develop an Individualized Education Program (IEP). This is a document that lists, among other things, the child's strengths and weaknesses, and what special education and related services the school will provide to address those needs. If the child is less than 3 years old, he or she will have an Individualized Family Service Plan, (IFSP). Parents can contact their state parent training and information center (PTI) or NICHCY for helpful information about IEP or IFSP development and the special education process.

Treatment of PDDNOS

On the whole, children with PDDNOS share the social and communicative disabilities found in children with Autistic Disorder. They often need services or treatments similar to those provided to children with autism.

Traditional Methods

No one therapy or method will work for all individuals with Autistic Disorder or PDDNOS. Many professionals and families will use a range of treatments simultaneously, including behavior modification, structured educational approaches, medications, speech therapy, occupational therapy, and counseling. These treatments promote more typical social and communication behavior and minimize negative behaviors (e.g., hyperactivity, meaningless, repetitive behavior, self-injury, aggressiveness) that interfere with the child's functioning and learning. There has been an increasing focus on treating preschool children with PDDNOS by working closely with family members to help the children cope with the problems encountered at home before they enter school. Many times, the earlier these children begin treatment, the better the outcome.

Addressing behavior issues. As children with PDDNOS struggle to make sense of the many things that are confusing to them, they do best in an organized environment where rules and expectations are clear and consistent. The child's environment needs to be very structured and predictable.

Many times a behavior problem indicates that the child is trying to communicate something—confusion, frustration or fear. Think of the child's behavior problem as a message to be decoded. Try to determine the possible cause of the behavior. Has the child's routine or

schedule changed recently? Has something new been introduced that may be distressing or confusing the child? When a child's communication skills improve, behavior problems often diminish—the child now has a means of expressing what is bothering him or her, without resorting to negative behavior.

The use of positive behavioral support strategies for these children has proved effective. It is important to remember that:

1. Programs should be designed on an individual basis, because children vary greatly in their disabilities and abilities. Treatment approaches that work in certain cases may not work in others.

2. Children with PDDNOS have difficulty generalizing from one situation to another. The skills they have learned in school tend not to be transferred to the home or other settings. It is very important to be consistent in the treatment of a problem across all areas of the child's life—school, community, and home. This encourages generalization of behavior changes.

3. A home-community-based approach, which trains parents and special education teachers to carry out positive behavioral support strategies, can be instrumental in achieving maximum results.

Appropriate educational program. Education is the primary tool for treating PDDNOS. Many children with PDDNOS experience the greatest difficulty in school, where demands for attention and impulse control are virtual requirements for success. Behavioral difficulties can prevent some children from adapting to the classroom. However, with appropriate educational help, a child with PDDNOS can succeed in school.

The most essential ingredient of a quality educational program is a knowledgeable teacher. Other elements of a quality educational program include:

- structured, consistent, predictable classes with schedules and assignments posted and clearly explained;
- information presented visually as well as verbally;
- opportunities to interact with nondisabled peers who model appropriate language, social, and behavioral skills;
- a focus on improving a child's communications skills using tools such as communication devices;
- reduced class size and an appropriate seating arrangement to help the child with PDDNOS avoid distraction;
- modified curriculum based on the particular child's strengths and weaknesses;
- using a combination of positive behavioral supports and other educational interventions; and
- frequent and adequate communication among teachers, parents, and the primary care clinician.

Medical treatment. The primary aim of medical treatment of children with PDDNOS is to ensure physical and psychological health. A good preventive health care program should include regular physical checkups to monitor growth, vision, hearing, and blood pressure; immunization according to schedule; regular visits to the dentist; and attention to diet and hygiene.

An effective medical treatment begins with a thorough medical assessment. The pretreatment assessment is essential for detecting existing medical conditions, such as a seizure disorder.

There is no one specific medication that helps all children with PDDNOS. Some medications have been found to be helpful, but for many children with autism or PDDNOS, medication levels need to be experimented with until the optimal combination and dosage are found. Since this differs with each child, there is no set medical treatment for children with PDDNOS but, rather, an individual medication regimen for each. Because of these complexities, in the eyes of many, medication therapy is viewed as a treatment to be used only when other types of treatment have been unsuccessful. It is important to note that medication can be effective and necessary for conditions that may coexist in children with PDDNOS, such as attention deficit disorder or obsessive compulsive disorder.

Parents' final decision on whether to use medication as part of their child's therapy is a personal one and should be respected and supported. Medication should *always* be used in conjunction with

A Mother's Story

Ryan, always in a whirl of activity, has had many labels. He was diagnosed with PDDNOS at age three and a half. When he went to preschool, his label was "developmentally delayed." Now he's 8 years old, and his label is "autistic." He spends most of his time in a 2nd grade class. He's doing great, but he still needs lots of extra help—speech therapy, occupational therapy, and physical therapy. He loves playing soccer with kids in his class. His disability is only one part of who he is; he also has lots of strengths and talents. Every day still has its challenges, but we love him. He's not a label—he's Ryan.

other therapies, and its effects should be monitored through feedback from the child, parents, and teachers.

Psychological treatment. Counseling may be helpful to families to help them adjust to raising a child with a disability. If the child is already attending a school program, both parents and teachers need to be told of the symptoms of PDDNOS and how those symptoms may affect the child's ability to function at home, in the neighborhood, in school, and in social situations. Psychologists can also provide ongoing assessments, school consultation, case management, and behavior training. Some children also benefit from counseling from an experienced practitioner who knows about PDDNOS. Family teamwork can ease the burden on the primary home caregiver, who needs a support system.

Other Therapies and Treatments

While exploring the treatment options available to help children with PDDNOS, parents and others may come across several therapies that can be used in conjunction with traditional ones. When considering one of these other therapies for a child, ask questions and carefully assess the program. It's important to ask for a written description of the program, including its length, the frequency of sessions, cost, and the rationale, philosophy, or purpose underlying the program. It's also important to investigate the credentials of the program director and staff and whether evidence exists to prove the effectiveness of the program, as well as the possible negative side effects. Here are some alternative programs available:

Facilitated communication. This is a method of encouraging people with communication impairments to express themselves. By providing physical assistance, a person, called a facilitator, helps the individual to spell words using a keyboard of a typewriter or computer or other letter display. Facilitation may involve hand-over-hand support or a simple touch on the shoulder. The individual with the impairment initiates the movement while the facilitator offers physical support.

Successful anecdotes of Facilitated Communication therapy have been reported and published over the past few years. They have also provoked considerable controversy, because generally they have not been supported by empirical research. It appears that Facilitated Communication has the potential for becoming a useful technique for some children with PDDNOS, particularly those who are precocious readers and good with other forms of communication such as computer and signs, but who also are severely impaired in verbal expression skills.

Auditory integration therapy (AIT). AIT uses a device that randomly selects low and high frequencies from a music source (a cassette or CD player) and then sends these sounds through headphones to the child.

There are anecdotes about the positive effects from AIT. Some of the results that have been reported include diminished sensitivity to sounds, more spontaneous speech, more complex language development, answering questions on topic, more interaction with peers, and more appropriate social behavior. However, significant results from a well-designed treatment study have not been available. It is still unclear how AIT works and whether people benefit from it.

Sensory integration therapy. Sensory integration is the nervous system's process of organizing sensory information for functional use. It refers to a normally occurring process in the brain that allows people to put sights, sounds, touch, taste, smells, and movements together to understand and interact with the world around them (Mailloux & Lacroix, 1992).

On the basis of assessment results, an occupational therapist who has been trained in sensory integration therapy guides an individual through activities that challenge his or her ability to respond appropriately to sensory stimulation. This type of therapy is directed toward improving how an individual's senses process stimulation and work together to respond appropriately. As with other therapies, no conclusive research demonstrates clear progress made through sensory integration therapy, but it is used in many areas.

The Lovaas method. This method (which is a type of Applied Behavior Analysis [ABA]), developed by psychologist Ivar Lovaas at UCLA, is an intensive intervention program originally designed for preschool-aged children with autism. It uses behavioral techniques—molding and rewarding desired behavior, and ignoring or discouraging undesirable actions—to achieve its goals. Generally, this method consists of 30 to 40 hours a week of basic language skills, behavior, and academic training. Therapy usually consists of 4 to 6 hours per day of one-on-one training, 5 to 7 days a week. Some research has shown remarkable

progress in about 50% of the children receiving this therapy. The Lovaas Method is getting wide attention, but, as with other therapies, it needs more study.

Vitamin therapy. Some anecdotal evidence has shown that Vitamin B6 and magnesium help children with autism and PDDNOS. The rationale for this is that Vitamin B6 helps the formation of neurotransmitters, which are thought to malfunction in such children (Dalldorf, 1995).

Dietary intervention. Some individuals with PDDNOS have been found to have food sensitivities or food allergies. Some parents choose to have their children evaluated by allergists and, based on the testing results, may eliminate or decrease foods to which their child shows the most sensitivity. For example, some foods seem to increase hyperactivity and autistic-like behavior. Eliminating these from the child's diet has been found to help decrease negative behaviors.

Anti-yeast therapy. Often the progression of autism and PDDNOS involves unusual behaviors and communication problems arising around the toddler stage, when many children are treated with antibiotics for problems such as middle ear infections. Antibiotics can upset the intestinal flora and possibly cause "yeast overgrowth." However, the existence of higher yeast levels in children with autism and PDDNOS could very well be coincidence (Dalldorf, 1995). Some parents have found that giving their child an anti-yeast medication decreases some negative behaviors. Some preliminary study findings support this type of treatment; however, the results are not conclusive.

Summary. Since well-designed studies of these therapies have not been conducted, their effectiveness in treating PDDNOS is unclear.

Helping Children at Home

Parents can use many techniques and treatments to help their young child with PDDNOS at home. These techniques should be discussed with other family members and the professionals who are working with the child, so that the individuals close to the child may employ the same methods. This will help the child generalize skills learned at home to other settings, such as at school and in the community. Parents can work at improving communication skills and social skills. See the "Additional Resources" at the end of this *Briefing Paper* for publications on techniques to use with children with PDDNOS.

Children with PDDNOS are not the only ones who need extra help and support. Parenting a child with special needs is a demanding task.

Finding a Parent Support Group

Children with PDDNOS are not the only ones who need extra help and support. Parenting a child with special needs is a demanding task. Learning and accepting that a child has a disability is a very emotional process. Initially, parents may feel alone and not know where to begin their search for information, assistance, and support. Parent groups offer parents and families a place to share information, give and receive emotional and practical support, and work as a team to address common goals.

Autism parent support groups are located throughout the country. Families whose child has PDDNOS can benefit from joining these support groups. See "Organizations" at the end of this publication for details.

Conclusion

Children with PDDNOS happen to have a unique disorder that will make certain parts of life more challenging. Many articles, booklets, and books contain useful information; however, these resources will probably not be found at the local library or bookstore. To get these materials, contact the organizations and publishers listed at the end of this *Briefing Paper.* The Internet is also a valuable information-collecting tool. Check out the helpful Web sites listed on page 15.

Learning more about the special needs of children with PDDNOS can be of enormous emotional and practical help to those who are involved with, and who care about, these special children.

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Organizations to Contact for Publication Lists:
These organizations do not have the resources to respond personally to individuals from all across the country, but they have a number of helpful publications available.

Indiana Resource Center for Autism, 2853 East 10th Street, Indiana University, Bloomington, IN 47408-2601. Telephone: (812) 855-6508 (V/TTY).
URL: http://www.isdd.indiana.edu/

New Jersey Center for Outreach and Services for the Autism Community (COSAC), 1450 Parkside Ave., Suite 22, Ewing, NJ 08638. Telephone: (609) 883-8100.
URL: http://members.aol.com/njautism

Helpful Web Sites:

Autism Society of America:
http//www.autism-society.org/

Autism at Yale Developmental Disabilities Home Page:
http://info.med.yale.edu/chldstdy/autism/welcome.html

Center for the Study of Autism: http://www.autism.com/

Division TEACCH Home Page:
http://www.unc.edu/depts/teacch/

Syracuse University Autism Resource Page:
http://web.syr.edu/~jmwobus/autism/

Organizations

Autism National Committee, 249 Hampshire Drive, Plainsboro, NJ 08536.

Autism Society of America, 7910 Woodmont Avenue, Suite 650, Bethesda, MD 20814. Telephone: (301) 657-0881; (800) 3-AUTISM.
URL: http://www.autism-society.org

National Information Center for Children and Youth with Disabilities (NICHCY), P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-695-0285; (202) 884-8200 (V/TTY). E-mail: nichcy@aed.org
URL: http://www.nichcy.org

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Director ..... Suzanne Ripley
Publications Coordinator ..... Lisa Küpper
Director of Information Services ..... Donna Waghorn
Editor ..... Mary Kate Gutiérrez
Author ..... Luke Y. Tsai, M.D.
Professor of Psychiatry and Pediatrics
Director, Developmental Disorders Clinic
University of Michigan Medical Center

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NICHCY

AED

Academy for Educational Development

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The Academy for Educational Development, founded in 1961, is an independent, nonprofit service organization committed to addressing human development needs in the United States and throughout the world. In partnership with its clients, the Academy seeks to meet today's social, economic, and environmental challenges through education and human resource development; to apply state-of-the-art education, training, research, technology, management, behavioral analysis, and social marketing techniques to solve problems; and to improve knowledge and skills throughout the world as the most effective means for stimulating growth, reducing poverty, and promoting democratic and humanitarian ideals.

Autism

Excerpted from: Neuwirth, S. (1997). *Autism* ("Decade of the Brain" series) (NIH Publication No. 97-4023). Bethesda, MD: National Institutes of Health.

Isolated in worlds of their own, people with autism appear indifferent and remote and are unable to form emotional bonds with others. Although people with this baffling brain disorder can display a wide range of symptoms and disability, many are incapable of understanding other people's thoughts, feelings, and needs. Often, language and intelligence fail to develop fully, making communication and social relationships difficult. Many people with autism engage in repetitive activities, like rocking or banging their heads, or rigidly following familiar patterns in their everyday routines. Some are painfully sensitive to sound, touch, sight, or smell.

Children with autism do not follow the typical patterns of child development. In some children, hints of future problems may be apparent from birth. In most cases, the problems become more noticeable as the child slips farther behind other children the same age. Other children start off well enough. But between 18 and 36 months old, they suddenly reject people, act strangely, and lose language and social skills they had already acquired.

As a parent, teacher, or caregiver you may know the frustration of trying to communicate and connect with children or adults who have autism. You may feel ignored as they engage in endlessly repetitive behaviors. You may despair at the bizarre ways they express their inner needs. And you may feel sorrow that your hopes and dreams for them may never materialize.

For more information contact:
National Institute of Mental Health
Information Resources and Inquires Branch
5600 Fishers Lane, Room 7C-02, MSC 8030
Bethesda, MD 20892-8030
Phone: (301) 443-4513 * Fax: (30) 443-4279
Fax back system:
Mental Health FAX4U 301-443-5158
E-mail: nimhinfo@nih.gov
URL: http://www.nimh.nih.gov

But there is help-and hope. Gone are the days when people with autism were isolated, typically sent away to institutions. Today, many youngsters can be helped to attend school with other children. Methods are available to help improve their social, language, and academic skills. Even though more than 60 percent of adults with autism continue to need care throughout their lives, some programs are beginning to demonstrate that with appropriate support, many people with autism can be trained to do meaningful work and participate in the life of the community.

Autism is found in every country and region of the world, and in families of all racial, ethnic, religious, and economic backgrounds. Emerging in childhood, it affects about 1 or 2 people in every thousand and is three to four times more common in boys than girls. Girls with the disorder, however, tend to have more severe symptoms and lower intelligence. In addition to loss of personal potential, the cost of health and educational services to those affected exceeds $3 billion each year. So, at some level, autism affects us all.

This booklet is provided by the National Institute of Mental Health (NIMH), the Federal agency that conducts and supports research on mental and brain disorders, including autism. NIMH is part of the National Institutes of Health (NIH), which is the Federal Government's primary agency for biomedical and behavioral research. Research on autism and related disorders is also sponsored by the National Institute of Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), and National Institute of Neurological Disorders and Stroke (NINDS).

NIMH scientists are dedicated to understanding the workings and interrelationships of the various regions of the brain, and to developing preventive measures and new treatments for disorders like autism that handicap people in school, work, and social relationships.

Up-to-date information on autism and the role of NIMH in identifying underlying causes and effective treatments are included in this pamphlet. Also described are symptoms and diagnostic procedures, treatment options, strategies for coping, and sources of information and support.

The individuals referred to in this brochure are not real, but their stories are based on interviews with parents who have children with autism.

Understanding the Problem

Paul

Paul has always been obsessed with order. As a child, he lined up blocks, straightened chairs, kept his toothbrush in the exact same spot on the sink, and threw a tantrum when anything was moved. Paul could also become aggressive. Sometimes, when upset or anxious, he would suddenly explode, throwing a nearby object or smashing a window. When overwhelmed by noise and confusion, he bit himself or picked at his nails until they bled. At school, where his schedule and environment could be carefully structured, his behavior was more normal. But at home, amid the unpredictable, noisy hubbub of a large family, he was often out of control. His behavior made it harder and harder for his parents to care for him at home and also meet their other children's needs. At that time-more than 10 years ago-much less was known about the disorder and few therapeutic options were available. So, at age 9, his parents placed him in a residential program where he could receive 24-hour supervision and care.

Alan

As an infant, Alan was playful and affectionate. At 6 months old, he could sit up and crawl. He began to walk and say words at 10 months and could count by 13 months. One day, in his 18th month, his mother found him sitting alone in the kitchen, repeatedly spinning the wheels of her vacuum cleaner with such persistence and concentration, he didn't respond when she called. From that day on, she recalls, "It was as if someone had pulled a shade over him." He stopped talking and relating to others. He often tore around the house like a demon. He became fixated on electric lights, running around the house turning them on and off. When made to stop, he threw a tantrum, kicking and biting anyone within reach.

Janie

From the day she was born, Janie seemed different from other infants. At an age when most infants enjoy interacting with people and exploring their environment, Janie sat motionless in her crib and didn't respond to rattles or other toys. She didn't seem to develop in the normal sequence, either. She stood up before she crawled, and when she began to walk, it was on her toes. By 30 months old, she still wasn't talking. Instead, she grabbed things or screamed to get what she wanted. She also seemed to have immense powers of concentration, sitting for hours looking at a toy in her hand. When Janie was brought to a special clinic for evaluation, she spent an entire testing session pulling tufts of wool from the psychologist's sweater.

What is Autism?

Autism is a brain disorder that typically affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Some people with autism are relatively high-functioning, with speech and intelligence intact. Others are mentally retarded, mute, or have serious language delays. For some, autism makes them seem closed off and shut down; others seem locked into repetitive behaviors and rigid patterns of thinking.

Although people with autism do not have exactly the same symptoms and deficits, they tend to share certain social, communication, motor, and sensory problems that affect their behavior in predictable ways.

Social symptoms

From the start, most infants are social beings. Early in life, they gaze at people, turn toward voices, endearingly grasp a finger, and even smile.

In contrast, most children with autism seem to have tremendous difficulty learning to engage in the give-and-take of everyday human interaction. Even in the first few months of life, many do not interact and they avoid eye contact. They seem to prefer being alone. They may resist attention and affection or passively accept hugs and cuddling. Later, they seldom seek comfort or respond to anger or affection. Unlike other children, they rarely become upset when the parent leaves or show pleasure when the parent returns. Parents who looked forward to the joys of cuddling, teaching, and playing with their child may feel crushed by this lack of response.

Children with autism also take longer to learn to interpret what others are thinking and feeling. Subtle social cues-whether a smile, a wink, or a grimace-may have little meaning. To a child who misses these cues, "Come here," always means the same thing, whether the speaker is smiling and extending her arms for a hug or squinting and planting her fists on her hips. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering.

To compound the problem, people with autism have problems seeing things from another person's perspective. Most 5-year-olds understand that other people have different information, feelings, and goals than they have. A person with autism may lack such understanding. This inability leaves them unable to predict or understand other people's actions.

Some people with autism also tend to be physically aggressive at times, making social relationships still more difficult. Some lose control, particularly when they're in a strange or overwhelming environment, or when angry and frustrated. They are capable at times of breaking things, attacking others, or harming themselves. Alan, for example, may fall into a rage, biting and kicking when he is frustrated or angry. Paul, when tense or overwhelmed, may break a window or throw things. Others are self-destructive, banging their heads, pulling their hair, or biting their arms.

Language difficulties

By age 3, most children have passed several predictable milestones on the path to learning language. One of the earliest is babbling. By the first birthday, a typical toddler says words, turns when he hears his name, points when he wants a toy, and when offered something distasteful, makes it very clear that his answer is no. By age 2, most children begin to put together sentences like "See doggie," or "More cookie," and can follow simple directions.

Research shows that about half of the children diagnosed with autism remain mute throughout their lives. Some infants who later show signs of autism do coo and babble during the first 6 months of life. But they soon stop. Although they may learn to communicate using sign language or special electronic equipment, they may never speak. Others may be delayed, developing language as late as age 5 to 8.

Those who do speak often use language in unusual ways. Some seem unable to combine words into meaningful sentences. Some speak only single words. Others repeat the same phrase no matter what the situation.

Some children with autism are only able to parrot what they hear, a condition called echolalia. Without persistent training, echoing other people's phrases may be the only language that people with autism ever acquire. What they repeat might be a question they were just asked, or an advertisement on television. Or out of the blue, a child may shout, "Stay on your own side of the road!"-something he heard his father say weeks before. Although children without autism go through a stage

where they repeat what they hear, it normally passes by the time they are 3.

People with autism also tend to confuse pronouns. They fail to grasp that words like "my," "I," and "you," change meaning depending on who is speaking. When Alan's teacher asks, "What is my name?" he answers, "My name is Alan."

Some children say the same phrase in a variety of different situations. One child, for example, says "Get in the car," at random times throughout the day. While on the surface, her statement seems bizarre, there may be a meaningful pattern in what the child says. The child may be saying, "Get in the car," whenever she wants to go outdoors. In her own mind, she's associated "Get in the car," with leaving the house. Another child, who says "Milk and cookies" whenever he is pleased, may be associating his good feelings around this treat with other things that give him pleasure.

It can be equally difficult to understand the body language of a person with autism. Most of us smile when we talk about things we enjoy, or shrug when we can't answer a question. But for children with autism, facial expressions, movements, and gestures rarely match what they are saying. Their tone of voice also fails to reflect their feelings. A high-pitched, sing-song, or flat, robot-like voice is common.

Without meaningful gestures or the language to ask for things, people with autism are at a loss to let others know what they need. As a result, children with autism may simply scream or grab what they want. Temple Grandin, an exceptional woman with autism who has written two books about her disorder, admits, "Not being able to speak was utter frustration. Screaming was the only way I could communicate." Often she would logically think to herself, "I am going to scream now because I want to tell somebody I don't want to do something." Until they are taught better means of expressing their needs, people with autism do whatever they can to get through to others.

Repetitive behaviors and obsessions

Although children with autism usually appear physically normal and have good muscle control, odd repetitive motions may set them off from other children. A child might spend hours repeatedly flicking or flapping her fingers or rocking back and forth. Many flail their arms or walk on their toes. Some suddenly freeze in position. Experts call such behaviors *stereotypies or self-stimulation.*

Some people with autism also tend to repeat certain actions over and over. A child might spend hours lining up pretzel sticks. Or, like Alan, run from room to room turning lights on and off.

Some children with autism develop troublesome fixations with specific objects, which can lead to unhealthy or dangerous behaviors. For example, one child insists on carrying feces from the bathroom into her classroom. Other behaviors are simply startling, humorous, or embarrassing to those around them. One girl, obsessed with digital watches, grabs the arms of strangers to look at their wrists.

For unexplained reasons, people with autism demand consistency in their environment. Many insist on eating the same foods, at the same time, sitting at precisely the same place at the table every day. They may get furious if a picture is tilted on the wall, or wildly upset if their toothbrush has been moved even slightly. A minor change in their routine, like taking a different route to school, may be tremendously upsetting.

Scientists are exploring several possible explanations for such repetitive, obsessive behavior. Perhaps the order and sameness lends some stability in a world of sensory confusion. Perhaps focused behaviors help them to block out painful stimuli. Yet another theory is that these behaviors are linked to the senses that work well or poorly. A child who sniffs everything in sight

may be using a stable sense of smell to explore his environment. Or perhaps the reverse is true: he may be trying to stimulate a sense that is dim.

Imaginative play, too, is limited by these repetitive behaviors and obsessions. Most children, as early as age 2, use their imagination to pretend. They create new uses for an object, perhaps using a bowl for a hat. Or they pretend to be someone else, like a mother cooking dinner for her "family" of dolls. In contrast, children with autism rarely pretend. Rather than rocking a doll or rolling a toy car, they may simply hold it, smell it, or spin it for hours on end.

Sensory symptoms

When children's perceptions are accurate, they can learn from what they see, feel, or hear. On the other hand, if sensory information is faulty or if the input from the various senses fails to merge into a coherent picture, the child's experiences of the world can be confusing. People with autism seem to have one or both of these problems. There may be problems in the sensory signals that reach the brain or in the integration of the sensory signals-and quite possibly, both.

Apparently, as a result of a brain malfunction, many children with autism are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells. Some children find the feel of clothes touching their skin so disturbing that they can't focus on anything else. For others, a gentle hug may be overwhelming. Some children cover their ears and scream at the sound of a vacuum cleaner, a distant airplane, a telephone ring, or even the wind. Temple Grandin says, "It was like having a hearing aid that picks up everything, with the volume control stuck on super loud." Because any noise was so painful, she often chose to withdraw and tuned out sounds to the point of seeming deaf.

In autism, the brain also seems unable to balance the senses appropriately. Some children with autism seem oblivious to extreme cold or pain, but react hysterically to things that wouldn't bother other children. A child with autism may break her arm in a fall and never cry. Another child might bash his head on the wall without a wince. On the other hand, a light touch may make the child scream with alarm.

In some people, the senses are even scrambled. One child gags when she feels a certain texture. A man with autism hears sound when someone touches a point on his chin. Another experiences certain sounds as colors.

Unusual abilities

Some people with autism display remarkable abilities. A few demonstrate skills far out of the ordinary. At a young age, when other children are drawing straight lines and scribbling, some children with autism are able to draw detailed, realistic pictures in three-dimensional perspective. Some toddlers who are autistic are so visually skilled that they can put complex jigsaw puzzles together. Many begin to read exceptionally early-sometimes even before they begin to speak. Some who have a keenly developed sense of hearing can play musical instruments they have never been taught, play a song accurately after hearing it once, or name any note they hear. Like the person played by Dustin Hoffman in the movie Rain Man, some people with autism can memorize entire television shows, pages of the phone book, or the scores of every major league baseball game for the past 20 years. However, such skills, known as islets of intelligence or savant skills are rare.

What Causes Autism?

It is generally accepted that autism is caused by abnormalities in brain structures or functions. Using a variety of new research tools to study human and animal brain growth, scientists are discovering more about normal development and how abnormalities occur.

The brain of a fetus develops throughout pregnancy.

Starting out with a few cells, the cells grow and divide until the brain contains billions of specialized cells, called neurons. Research sponsored by NIMH and other components at the National Institutes of Health is playing a key role in showing how cells find their way to a specific area of the brain and take on special functions. Once in place, each neuron sends out long fibers that connect with other neurons. In this way, lines of communication are established between various areas of the brain and between the brain and the rest of the body. As each neuron receives a signal it releases chemicals called neurotransmitters, which pass the signal to the next neuron. By birth, the brain has evolved into a complex organ with several distinct regions and subregions, each with a precise set of functions and responsibilities.

Different parts of the brain have different functions

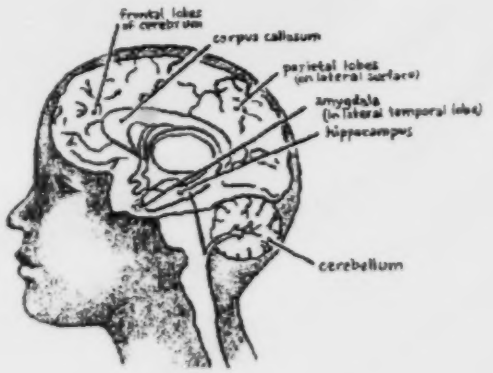
- The hippocampus makes it possible to recall recent experience and new information
- The amygdala directs our emotional responses
- The frontal lobes of the cerebrum allow us to solve problems, plan ahead, understand the behavior of others, and restrain our impulses
- The parietal areas control hearing, speech, and language
- The cerebellum regulates balance, body movements, coordination, and the muscles used in speaking
- The corpus callossum passes information from one side of the brain to the other

But brain development does not stop at birth. The brain continues to change during the first few years of life, as new neurotransmitters become activated and additional lines of communication are established. Neural networks are forming and creating a foundation for processing language, emotions, and thought.

However, scientists now know that a number of problems may interfere with normal brain development. Cells may migrate to the wrong place in the brain. Or, due to problems with the neural pathways or the neurotransmitters, some parts of the communication network may fail to perform. A problem with the communication network may interfere with the overall task of coordinating sensory information, thoughts, feelings, and actions.

Researchers supported by NIMH and other NIH Institutes are scrutinizing the structures and functions of the brain for clues as to how a brain with autism differs from the normal brain. In one line of study, researchers are investigating potential defects that occur during initial brain development. Other researchers are looking for defects in the brains of people already known to have autism.

Scientists are also looking for abnormalities in the brain structures that make up the limbic system. Inside the limbic system, an area called the amygdala is known to help regulate aspects of social and emotional behavior. One study of high-functioning children with autism found that the amygdala was indeed impaired but that another area of the brain, the hippocampus, was not. In another study, scientists followed the development of monkeys whose amygdala was disrupted at birth. Like children with autism, as the monkeys grew, they became increasingly withdrawn and avoided social contact.



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Differences in neurotransmitters, the chemical messengers of the nervous system, are also being explored. For example, high levels of the neurotransmitter serotonin have been found in a number of people with autism. Since neurotransmitters are responsible for passing nerve impulses in the brain and nervous system, it is possible that they are involved in the distortion of sensations that accompanies autism.

NIMH grantees are also exploring differences in overall brain function, using a technology called magnetic resonance imaging (MRI) to identify which parts of the brain are energized during specific mental tasks. In a study of adolescent boys, NIMH researchers observed that during problem-solving and language tasks, teenagers with autism were not only less successful than peers without autism, but the MRI images of their brains showed less activity. In a study of younger children, researhcers observed low levels of activity in the parietal areas and the corpus callosum. Such research may help scientists determine whether autism reflects a problem with specific areas of the brain or with the transmission of signals from one part of the brain to another.

Each of these differences has been seen in some but not all the people with autism who were tested. What could this mean? Perhaps the term autism actually covers several different disorders, each caused by a different problem in the brain. Or perhaps the various brain differences are themselves caused by a single underlying disorder that scientists have not yet identified. Discovering the physical basis of autism should someday allow us to better identify, treat, and possibly prevent it.

Factors affecting brain development

But what causes normal brain development to go awry? Some NIMH researchers are investigating genetic causes-the role that heredity and genes play in passing the disorder from one generation to the next. Others are looking at medical problems related to pregnancy and other factors.

Heredity. Several studies of twins suggest that autism-or at least a higher likelihood of some brain dysfunction-can be inherited. For example, identical twins are far more likely than fraternal twins to both have autism. Unlike fraternal twins, which develop from two separate eggs, identical twins develop from a single egg and have the same genetic makeup.

It appears that parents who have one child with autism are at slightly increased risk for having more than one child with autism. This also suggests a genetic link. However, autism does not appear to be due to one particular gene. If autism, like eye color, were passed along by a single gene, more family members would inherit the disorder. NIMH grantees, using state-of-the-art gene splicing techniques, are searching for irregular segments of genetic code that the autistic members of a family may have inherited.

Some scientists believe that what is inherited is an irregular segment of genetic code or a small cluster of three to six unstable genes. In most people, the faulty code may cause only minor problems. But under certain conditions, the unstable genes may interact and seriously interfere with the brain development of the unborn child.

A body of NIMH-sponsored research is testing this theory. One study is exploring whether parents and siblings who do not have autism show minor symptoms, such as mild social, language, or reading problems. If so, such findings would suggest that several members of a family can inherit the irregular or unstable genes, but that other as yet unidentified conditions must be present for the full-blown disorder to develop.

Pregnancy and other problems. Throughout pregnancy, the fetal brain is growing larger and more complex, as new cells, specialized regions, and communication networks form. During this time, anything that disrupts normal brain development may have lifelong effects on the child's sensory, language, social, and mental functioning.

For this reason, researchers are exploring whether certain conditions, like the mother's health during pregnancy, problems during delivery, or other environmental factors may interfere with normal brain development. Viral infections like rubella (also called German measles), particularly in the first three months of pregnancy, may lead to a variety of problems, possibly including autism and retardation. Lack of oxygen to the baby and other complications of delivery may also increase the risk of autism. However, there is no clear link. Such problems occur in the delivery of many infants who are not autistic, and most children with autism are born without such factors.

Are There Accompanying Disorders?

Several disorders commonly accompany autism. To some extent, these may be caused by a common underlying problem in brain functioning.

Mental retardation

Of the problems that can occur with autism, mental retardation is the most widespread. Seventy-five to 80 percent of people with autism are mentally retarded to some extent. Fifteen to 20 percent are considered severely retarded, with IQs below 35. (A score of 100 represents average intelligence.) But autism does not necessarily correspond with mental impairment. More than 10 percent of people with autism have an average or above average IQ. A few show exceptional intelligence.

Interpreting IQ scores is difficult, however, because most intelligence tests are not designed for people with autism. People with autism do not perceive or relate to their environment in typical ways. When tested, some areas of ability are normal or even above average, and some areas may be especially weak. For example, a child with autism may do extremely well on the parts of the test that measure visual skills but earn low scores on the language subtests.

Seizures

About one-third of the children with autism develop seizures, starting either in early childhood or adolescence. Researchers are trying to learn if there is any significance to the time of onset, since the seizures often first appear when certain neurotransmitters become active.

Since seizures range from brief blackouts to full-blown body convulsions, an electroencephalogram (EEG) can help confirm their presence. Fortunately, in most cases, seizures can be controlled with medication.

Fragile X

One disorder, Fragile X syndrome, has been found in about 10 percent of people with autism, mostly males. This inherited disorder is named for a defective piece of the X-chromosome that appears pinched and fragile when seen under a microscope.

People who inherit this faulty bit of genetic code are more likely to have mental retardation and many of the same symptoms as autism along with unusual physical features that are not typical of autism.

Tuberous Sclerosis

There is also some relationship between autism and Tuberous Sclerosis, a genetic condition that causes abnormal tissue growth in the brain and problems in

other organs. Although Tuberous Sclerosis is a rare disorder, occurring less than once in 10,000 births, about a fourth of those affected are also autistic. Scientists are exploring genetic conditions such as Fragile X and Tuberous Sclerosis to see why they so often coincide with autism. Understanding exactly how these conditions disrupt normal brain development may provide insights to the biological and genetic mechanisms of autism.

What Hope Does Research Offer?

Research continues to reveal how the brain-the control center for thought, language, feelings, and behavior-carries out its functions. The National Institute of Mental Health (NIMH) funds scientists at centers across the Nation who are exploring how the brain develops, transmits its signals, integrates input from the senses, and translates all this into thoughts and behavior. In recognition of growing scientific gains in brain research, the President and Congress have officially designated the 1990s as the "Decade of the Brain."

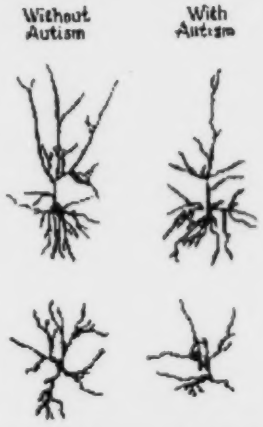
There are new research initiatives at NIH sponsored by NIMH, NICHD, NINDS, and NIDCD. As a result, today as never before, investigators from various scientific disciplines are joining forces to unlock the mysteries of the brain. Perspective gained from research into the genetic, biochemical, physiological, and psychological aspects of autism may provide a more complete view of the disorder.

Every day, NIH-sponsored researchers are learning more about how the brain develops normally and what can go wrong in the process. Already, for example, scientists have discovered evidence suggesting that in autism, brain development slows at some point before week 30 of pregnancy.

Scientists now also have tools and techniques that allow them to examine the brain in ways that were unthought of just a few years ago. New imaging techniques that show the living brain in action permit scientists to observe with surprising clarity how the brain changes as an individual performs mental tasks, moves, or speaks. Such techniques open windows to the brain, allowing scientists to learn which brain regions are engaged in particular tasks.

In addition, recent scientific advances are permitting scientists to break new ground in researching the role of heredity in autism. Using sophisticated statistical methods along with gene splicing-a technique that enables scientists to manipulate the microscopic bits of genetic code-investigators sponsored by NIH and other institutions are searching for abnormal genes that may be involved in autism. The ability to identify irregular genes-or the factors that make a gene unstable-may lead to earlier diagnoses. Meanwhile, scientists are working to determine if there is a genetic link between autism and other brain disorders commonly associated with it, such as Tourette Disorder and Tuberous Sclerosis. New insights into the genetic transmission of these disorders, along with newly gained knowledge of normal and abnormal brain development shoul provide important clues the causes of autism.

Brain Cell Defects



Research shows stunted growth-less branching-in certain nerve cells of people with autism.

A key to developing our understanding of the human brain is research involving animals. Like humans, other primates, such as chimpanzees, apes, and monkeys, have emotions, form attachments, and develop higher-level thought processes. For this reason, studies of their brain functions and behavior shed light on human development.

Animal studies have proven invaluable in learning how disruptions to the developing brain affect behavior, sensory perceptions, and mental development and have led to a better understanding of autism.

Ultimately, the results of NIMH's extensive research program may translate into better lives for people with autism. As we get closer to understanding the brain, we approach a day when we may be able to diagnose very young children and provide effective treatment earlier in the child's development. As data accumulate on the brain chemicals involved in autism, we get closer to developing medications that reduce or reverse imbalances.

Someday, we may even have the ability to prevent the disorder. Perhaps researchers will learn to identify children at risk for autism at birth, allowing doctors and other health care professionals to provide preventive therapy before symptoms ever develop. Or, as scientists learn more about the genetic transmission of autism, they may be able to replace any defective genes before the infant is even born.

Because of Alex....In a Word

by Clarence E. Schutt, Ph.D.

In dreams our deepest wishes become true. Our unconscious brains work unceasingly to combine experiences from long ago with those of yesterday, and relay these illusions to a place where anxious thoughts dissolve. In my dreams, my son Alex speaks. His voice is clear, his thoughts and questions sharp and cleverly worded. His speech is so natural that the miracle of it dawns on me only slowly. My joyful cries wake me, returning me to a world where Alex still can't speak, but leaving me to wonder "does he talk in his dreams?" What a comfort it would be to know that for nine hours out of every twenty-four Alex can experience the gift of speech like nearly everyone else.

What exactly is a word? This question undoubtedly caused sleepless nights for some of the greatest of twentieth century philosophers: Russell, Wittgenstein, Putnam, Quine, and Rorty, who struggled to explain how words can represent the world, including the thoughts of others, to our minds. It is the deepest of questions because of the relationship words bear to thought itself. Can one think without words? Is moral behavior possible without language? In these heady realms, autism should easily be accorded the label of the "most philosophical of all human afflictions."

Physiologists have a simpler explanation. Words are the result of the controlled passage of air over the voice-box, across our tongues and teeth, and through our lips. Utterances are entirely the result of a beautifully orchestrated series of muscular contractions in the diaphragm, throat, and tongue, as air passes over them, all while our eyes are scanning text or face and our ears register the sounds to which we will respond. The muscles are set into motion by nerves that are controlled by various ganglia of nerve cells, linking conscious thought to autonomic movements. Like walking, we seem to do it effortlessly (once we learn how). It is all a matter of triggering what were once called "programs of the brain" to produce the nerve signals in the proper sequence to activate the muscles involved. Sensors on each muscle, which are themselves extended neuronal cells whose axons terminate at the surface of the muscles, report back instantaneously on the strength being exerted by each muscle. This information allows us to make fine adjustments in our performance. Some are better at it than others, and practice makes perfect.

What happens in my sleeping brain when words Alex can never have spoken appear so naturally on his lips in my dreams? Why doesn't endless repetition improve Alex's vocabulary? What are the causes of involuntary movements in our children's facial and bodily muscles?

Such questions no longer seem odd or impossible to comprehend. The robust new field of "cognitive neuroscience" is leading us closer to the secrets of language. Using PET scans that can map moment-by-moment changes in oxygen consumption in working brains, it is possible to see which areas of the brain are activated in response to specific cognitive challenges. Relatively easy linguistic tasks for normal subjects, like repeating a list of commonly used nouns, seem hardly to tax the brain. Little seems to happen between a prompt from the investigator and the production of the expected string of words from the subject. However, when subjects are asked to think of novel noun-verb combinations or to solve complicated puzzles, their brains appear to be active in several distinct areas in particular order.

Although the classical "language areas" of Broca and Wernicke (so beloved by popular writers on the brain) are clearly important, it is clear that many regions must work in concert, especially in complex social conversations. PET scans reveal, for instance, the close proximity of the "motor" areas responsible for speech production and the "cognitive" areas involved in processing sensory information. The "executive" and "memory" regions all seem to light up when responses to the spoken word are being sent down the line to the muscles that cause the noises we call words. It is beginning to make sense.

Social context changes the pattern of responses. A small brain structure called the amygdala swings into action. Every instant of social life is a moment of creation, during which our brains map the present onto our stored memories and associations to produce a combination of past and present never before seen. Each word, every facial expression, all uncomfortable shifts in gaze or posture result when webs of sensory field neurons combine with memory nets, where values and learned responses reside, and play a tune on the nerves that control our muscles. Our movements and responses change what others perceive in us. Our worlds meld and join.

Interpreting the science in this way leads to an optimistic view of human nature. We are all different. The impossibly large number of experiences we each have all register differently and combine in different ways in our minds. If we think of higher things and dream about a future without autism, the world might even get better.

And Alex may one day speak of his dreams with me. ◆

Clarence E. Schutt, Ph.D. is Executive Vice President and Secretary of NAAR. Dr. Schutt is Professor of Chemistry at Princeton University, where he is also Associated Faculty of the Molecular Biology Department, Director of the Graduate Programs in Molecular Biophysics and Chemistry and a Member of the Program in Neuroscience. He is the parent of a 12-year-old son with autism.

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At Home With Autism

VIKI GAYHARDT

"As parents, we've taken the first step in community involvement just by showing up with our kids, and it's an agonizing step for us to make sometimes just to go to the grocery store with our kids who have autism/PDD. It's up to neighbors, parents of schoolmates, librarians, teachers, sport coaches, members of church congregations, and other community members to take that second step to keep us wanting to continue being a part of society."

I'm really encouraged by Danielle's story. There's hope. I'm going to balance the scale a little bit here. My name is Viki Gayhardt. Autism/PDD is a hidden disability and, without a doubt, our children

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are some of the most physically beautiful children on earth. I think it's because of this reason that their needs are often misunderstood, underestimated, or just completely overlooked. This mistake is especially true for the less involved, more verbal children. I have two children: six year old Justine and two and a half year old Vinny. Both my children have been diagnosed with PDD-NOS, but today I'm going to tell Jussy's story.

Justine was my first child after seven years of marriage. I was working full-time and quit my job to stay home with her. She received

150% of my attention, at least. I was very concerned when her peers started to skyrocket past her in various areas of development. Her idiosyncratic behaviors were plentiful. The list goes on and on. Justine was very active. She rocked. She lined up toys—miles and miles of toys all around the house. She liked to put hairy things in her mouth. She'd bite the hair off those little troll dolls. She always had something swirling around on her tongue. Above all, she would recite lines from movies with such character and animation that people would say, "That kid's got to be on Broadway," and urge me to get her an agent. "She's got to be a model, she's got to be in the movies."

When Justine was two and a half she began to withhold her bowel movements. That was a lot of fun, let me tell you. This behavior really became a serious medical issue, and it was at that point that I discussed some of the other concerning behaviors with her nurse practitioner. We felt it was time to see a specialist, not only about the toileting issue, but to consider the possibility of Attention Deficit

Disorder and Pervasive Developmental Disorder. ADD and PDD were not new concepts to me because I have a nephew who was diagnosed in the late 80's. PDD was always in the back of my mind. I felt that the disorder could be a genetic thing, perhaps, and maybe something I should watch out for with my own kids. It was from that referral that six months later we found ourselves at a medical center.

The two clinicians who saw Justine that day saw her on a really good day. That's how it goes with autism, there's good days and bad days. She was in her glory having two people on the floor playing with her, surrounded by brand new toys. So they concluded that Justine was well within the norm for a child of three. Perhaps a little overactive, a little domineering, but within the norm nevertheless. They advised us to get her into a preschool, and if we were still concerned they said to come back in about a year.

We were still concerned, needless to say. It wasn't until one of her preschool teachers said to me, "It's almost like when you're talking to her she's not processing what you're saying;" that comment was validation. That's my favorite word, validation. Finally, someone was recognizing what I had been seeing all along, and finally it was someone other than me recognizing it. That was the real drive I needed to pursue a diagnosis. I recruited the help of a friend of mine, who's also an Early Interventionist. I asked her if she would maybe do some research for me, to find something that we hadn't thought of yet.

My friend unearthed an article on Fragile X Syndrome. I remember reading this article and thinking, "My God this sounds just like my daughter." It was because of that article we found ourselves back at the medical center about thirteen months after our initial visit. This time we would see a geneticist to specifically question Fragile X Syndrome (not knowing at the time the relationship between autism and Fragile X Syndrome). The geneticist took one look at Jussy and said, "I don't think we're looking at Fragile X. I think this is a Pervasive Developmental Disorder." I didn't know if I wanted to kill

the messenger at that point or hug the messenger, but I did know that I was very bitter about the thirteen months that had passed. I didn't understand why our daughter hadn't been diagnosed at her initial visit. The geneticist said that he wanted the diagnosis of PDD to be confirmed by a developmental pediatrician, but it would be another six months before we could get in to see him. This concerned me, and I expressed those concerns with the staff, who then arranged to have us seen sooner. Finally, in November of 1994, Justine was diagnosed with PDD-NOS.

One month later my son, Vince, was at his ten month well-child visit and they noted that he was showing some signs of developmental delay. His is a different story, but it gives you an idea of what I was going through that following year. Not only was I dealing with the grief of my daughter's diagnosis and trying to learn about autism/PDD, but I was getting Justine into the special education process (learning about IEP's and my rights), as well as getting Vinny into the Early Intervention process. It was a crazy year, and forty pounds later I can say that Prozac and Ben & Jerry were my best friends.

At the time of Justine's diagnosis I remember that I had asked the staff if they had any literature I could take home to read about autism/PDD that would give me some basic information about what we were dealing with. The only thing they had that day was an article from a Zero-to-Three magazine. I brought it home to read and it just went right over my head. It was a little too technical for me to understand. I really just needed some basic information. That was the inspiration for the booklet Crossing Bridges that I co-authored with two other mothers of children with autism, Barbara Peerenboom and Roxanne Campbell. Designed to be a tool for physicians to deliver with the diagnosis, Crossing Bridges offers parents basic information on autism/PDD, and answers questions such as "What's the difference between autism and PDD?" and "What does perseveration mean?" When we were writing this booklet, my spelling check wouldn't even

recognize perseveration as a real word, but instead wanted to change it to preservation!

The best advice the developmental pediatrician gave me on the day Justine was diagnosed was to contact the local support group leader, who is also a mother of a child with autism/PDD. I found other parents to be our greatest resource—their help was invaluable, and it still is to this day. Not only to me, but to our local Special Education (SPED) Director. One day he confessed to me that he really didn't know what he was dealing with concerning autism/PDD. He wanted to learn more. It was our local support group leader who he called to get further direction and guidance. I think I have a really good relationship with the school and I feel we've built that relationship on a mutual desire: to learn more about autism/PDD. We've been learning together.

My pace has been faster than the school's, and I think this is the biggest obstacle. I know if I'm researching an intervention, a treatment or a therapy, and I present it to the SPED Team, it doesn't hold much weight coming from me. It seems like the exact same advice has to come from a professional before the SPED Team is ready to consider that advice. I really think persistence is the key to overcoming obstacles when dealing with school districts and early intervention teams. But, in the meantime don't forget to say "thank you," because everyone is trying to work together. Professionals are people too; they need a pat on the back once in a while, to be told that they're doing a good job, and that it's appreciated.

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I decide on a particular intervention by gathering the information in front of me and asking myself, "Okay, as a mother of two children with special needs, is this something I'm realistically going to be able to do?" For example, every time my kids start to self-regulate am I going to run in there, intervene and redirect them into something more constructive? Well no, I can't do that. I can't be on them every second. So you could safely say that I wouldn't be a good candidate for a home-based (LOVAAS-type) program. But what I can do is take that kind of intervention and modify it. I can do two fifteen-minute sessions a day with my kids, where I really get down on the floor and play with them and get into what they are doing. I know that when I start a new intervention with my kids, I usually do it with great gusto, but sometimes I later learn that it requires much more than what I can realistically carry through. It's from that trial-and-error process that I've learned my capacity as a primary care giver, and I've recognized my strengths and weaknesses. I've concluded that I am not a super, Type-A Mom. Along with the admission that you can't do it all comes a lot of feelings of inadequacy and guilt. I'm dealing with those emotions right now.

Outside of early interventionists and school personnel, I receive private support from a few friends, some select members of the church congregation, and the families of the children that have been in school with Jussy for about two years now. What makes them more supportive in my mind is that they have gotten to know Justine on a personal level. They see her as Justine, who's a kid first, and they have had time to get comfortable with the autism. They are not threatened by it over the course of time.

Regretfully, but truthfully, I'll admit that community inclusion has been a painful experience for me. We've tried story hours, soccer, T-ball, church events, school events, old home events, and it's always a constant, painful reminder that autism will always challenge my family and separate us. I recently learned that there is a clinical term for this kind of mourning: it's called chronic sorrow. A good example of

chronic sorrow would be a scene that took place at my daughter's sixth birthday party. We had it at a McDonald's PlayPlace, and we invited 20 kids from Justine's kindergarten. One of the children was a little boy who has autism/PDD, who was a bit more involved than Justine. On one side of the PlayPlace was that little boy with his Mom. She was really struggling to keep him focused and prevent him from falling apart in this total sensory overload situation. On the other side of the PlayPlace were the parents of the typical kids, I call them "tippies." The tippies were laughing, drinking their coffee, and eating their burgers. They were totally oblivious to what a luxury their circumstances would be for the Mom on the other side. It was an opportunity for me to step back and watch and be objective for a change, but the only thing I could really see was that mother's pain. I could read it on her face. "God, get me through this next hour. I want to get out of here, I want to get out of here." She and I discussed this afterwards, and we talked about how hard it is—it doesn't matter how long you do it, or how often you practice. That separateness is always going to be there. It's chronic sorrow.

For the most part I think that communities are really excelling in including and supporting children with autism/PDD, but I'm finding that support breaks down when it comes to we parents. Parents of children with special needs are often ignored or forgotten in the inclusion process, and you've got to remember that as the primary care givers, the well being of the children depends upon our well being. Parents need support and positive reinforcement too!

I have a few suggestions for community members wishing to help parents who have children with autism/PDD. The first thing would be to acquire a better understanding of autism/PDD, and, more specifically, the wide range of abilities within the autism spectrum. I have this fantasy, and I don't really think it's beyond reality. I'm thinking that every town library could conduct an awareness campaign. They could recruit the help of the PTO, the recreation department, the churches, fire departments and Elks Clubs, and it

would snowball into this big beautiful thing like what Jerry Lewis has done for his children through comedy. Can you imagine what Sylvester Stallone could do for our kids with Rambo tactics! (Stallone has a son who has autism.)

The second suggestion would be to respect what a parent chooses for their child with autism/PDD, or any disability. I've chosen inclusion for Justine and I've admitted it's really hard for me. It takes a lot of courage and tons of patience and energy. The easiest thing for me to do would be to stay home and hide. But I'm doing it the hard way, so I'd like a little bit of respect for my effort instead of being criticized and judged, and believe me that happens on a daily basis. Above all, offer parents *silent* support. I stress silent because oftentimes people think they are being supportive when they are actually being condescending. Don't take me wrong, the things people say are well intentioned. My favorite is, "Viki, God gives us no more than we can handle." My definition of "handle" is 100mg of Zolof, weekly grief therapy appointments, and daily doses of Hershey's with almonds! Oh yeah, I'm handling it.

A perfect example of an opportunity where someone could offer silent support is the McDonald's scenario. Buy that Mom a cup of coffee and the child some french fries, go over there and talk to her. She's going to appreciate the companionship. The kid is going to be engaged by the french fries, and of course you're going to get some practice. You're going to learn that this child with autism isn't going to bite you. I think it's the practice that's going to make it easier for you to realize that we're just people and our kids are just kids. Parents have peer pressure too, and I think that for me it's very comforting when a peer recognizes that I'm struggling. The community events in which I have felt the most successful are when someone has been there to hold *my* hand. Don't wait for a parent to ask for help, because often times we don't know what we need. We're so busy getting through the moment, that we don't have time to stop and contemplate our own needs.

As parents, we've taken the first step in community involvement just by showing up with our kids, and it's an agonizing step for us to make sometimes just to go to the grocery store with our kids who have autism/PDD. It's up to neighbors, parents of classmates, librarians, teachers, sport coaches, members of church congregations, and other community members to take that second step to keep us wanting to continue being a part of society. Give that Mom at McDonald's a reason for wanting to return to another birthday party. I know that personally, I would welcome anyone's desire to be more informed and comfortable with autism/PDD.

I'm going to embrace any effort by the community to accept and understand me and my family, and our basic need to feel like we belong.

State-of-the-Science in Autism: Report of the Autism Working Group to the National Institutes of Health (NIH)

Executive Summary

by Marie M. Bristol[1]

New findings of the mechanisms underlying other developmental disorders such as Fragile X syndrome and insulin dependent diabetes mellitus encouraged parents of children with autism to work for similar advances in the study of autism. On April 10 and 11, 1995, the NIH, in response to a Congressional request, assembled a working group of distinguished scientists to assess the state of the science in autism, identify gaps in knowledge, and make recommendations to the NIH regarding promising areas for future research. Participants in the meeting, which was held at the NIH, include researchers in autism and related areas, a scientist with autism, representatives of the Autism Society of America and the Autism National Committee, and invited consultants.

Follow-up sessions were held at the national conferences of the Autism Society of America, which had initiated the NIH conference, and the Autism National Committee, which had endorsed it. Thoughtful comments on the preliminary draft of this report were received from the April conference participants, at the followup parent conferences, and over a four-month period from other professionals, parents, and self-advocates. The full report of the Autism Working Group to the NIH and summaries of major presentations are in press in a special Spring (1996) issue of the *Journal of Autism and Developmental Disorders.*

The National Institute of Child Health and Human Development (NICHD) was the lead agency for the NIH conference which was cosponsored by the National Institute on Deafness and Other Communication Disorders (NIDCD), the National Institute of Mental Health (NIMH), and the National Institute of Neurological Disorders and Stroke (NINDS). In keeping with the Congressional mandate, questions of interest to the NIH formed the basis for the conference and served as the framework for this report. These questions were developed by the NIH Inter-Institute Autism Conference Coordinating Committee: Drs. Duane Alexander (NICHD), conference convener; Judith Cooper (NIDCD); Felix de la Cruz (NICHD); Peter Jensen (NIMH); Marie Bristol (NICHD), Conference Chair; Rebecca del Carmen (NIMH); Ralph Nitkin (NICHD); and Giovanna Spinella (NINDS).

Highlights of the full report follow.

Can We Diagnose Autism?

◆ For the first time, there are consistent criteria for the diagnosis of autism spectrum disorders in both the American and international diagnostic systems. However, screening and diagnostic procedures for children under the age of three are urgently needed.

◆ Longitudinal studies are needed to describe the lifespan course of development of individuals with autism spectrum disorders.

◆ Studies are needed of additional behavioral or developmental features often observed in autism, e.g., sensory hypersensitivity, as well as features that represent separate, but co-occurring disorders, e.g., obsessive-compulsive disorder (OCD).

◆ Identification of one or more biological markers (e.g., genetic and/or neurochemical) is an important topic of research.

[1] Now Marie Bristol-Power

How Common Is Autism?

◆ Autism is not a rare disorder. Prevalence estimates for Canada and Japan indicate rates may be as high as 1 per 1000. If the full range of autism spectrum disorders is included, rates may be more than 2 per 1000. Autism, then, is more common than Down syndrome, childhood cancer, or Fragile X syndrome.

◆ As a result of the NIH conference, screening for autism will be included in research being conducted by a national network of epidemiologic sites studying childhood disorders.

◆ Given the chronicity of autism, research is needed on the costs of various types of lifetime support for persons with autism and their families.

What Causes Autism?

◆ Available evidence indicates that the initial brain abnormalities in autism may occur during the early period of brain development, i.e., before birth. Various possible causes (e.g., infectious, metabolic, immunological, neurophysiologic, environmental) that may lead to similar patterns of development, which result in autism.

◆ For at least a significant subgroup of persons with autism, there appears to be a genetic susceptibility that most likely involves more than one gene and may differ across families (i.e., different genes may be responsible in different families).

◆ Experts agree that the identification of gene(s) for autism will be greatly facilitated by the fine-resolution genetic map being developed by the NIH National Center for Human Genome Research (NCHGR).

◆ Evidence suggests that there may be a higher prevalence of a variety of problems in pregnancy, at birth, or even after birth in children with autism than is the case for comparable, non-autistic children. However, these problems are not consistent across cases of autism nor specific only to autism. These problems do not appear to cause autism, but may be reflections that fetal or neonatal development was compromised in some way.

What Brain Structures or Functions Are Affected?

◆ There is evidence of functional and structural abnormalities in several brain regions in persons with autism. These regions include the amygdala, hippocampus, septum, mammillary bodies, and the cerebellum. Autistic brains are slightly larger and heavier. Differences have been observed in terms of size and in the number and size of certain cells within the central nervous system in autism. Which differences are unique to autism remains to be demonstrated.

◆ There is a pressing need for the use of brain and tissue banks to expand understanding of neuroanatomic findings and neurotransmitter pathways.

◆ Neuropsychological studies have found consistent deficits in some brain functions, while demonstrating that other functions are remarkably spared. Combining neuropsychologic techniques with structural and functional imaging will provide powerful tools for understanding these deficits and strengths. In these studies, standardized procedures are needed for diagnosis, composition of comparison groups, imaging, psychological testing, and interpretation of results.

◆ Gene mutations which may be related to the neurochemical abnormalities seen in autism, such as the serotonin increases in brain and platelets, can now be tested in animal models. Eventually this will lead to the design of effective pharmacological treatments for the core symptoms of autism. Animal studies are also informative for explaining the timing and type of lesions that affect cognitive and social development.

What Aspects of Communication and Social/Emotional Development Are Affected?

◆ Verbal persons with autism often have strengths in phonology (correct sound production) and syntax (rules for putting words together), but difficulty in pragmatics (the functional use of language in social situations).

◆ The capacity to initiate social interaction using verbal and/or nonverbal (e.g., gaze or gestures) means may be specifically impaired in autism, affecting language and social behavior. This may be accounted for, at least in part, by a social cognitive deficit, a sort of "mindblindness" that is being tested by research conceptualized as a "theory of mind".

◆ Many individuals with autism lack speech and have limitations in gestural communication and in the use of augmentative communication systems. These problem areas may be caused or complicated by specific sensory difficulties and/or general motor or more specific motor/speech impairments. There is almost no systematic research in this area.

◆ Research is urgently needed on predictors of which children will develop speech, lose speech (which occurs in up to one third of children with autism who initially develop speech), and on the development, function, and treatment of unconventional verbal behavior (e.g., echolalia, perseverative speech, incessant questioning).

What are Some Important Goals for Research on Medical Interventions?

◆ Although medication may help control some of the symptoms that interfere with learning and social interaction, pharmacological interventions designed specifically for the core symptoms of autism are needed.

◆ Rigorous evaluation of the effectiveness of currently available medical approaches to treatment, including alternative or complementary medical therapies, is needed. Improvements over placebo/control evaluation designs are also needed.

◆ Intervention research requires well-trained investigators, longitudinal research designs, and the infrastructure needed to support such research.

◆ Research has the potential to facilitate the creation of newer approaches to treatment that utilize advances in neuroscience, genetics, immunology, and other neurobiologic, behavioral, and pharmacologic fields.

What is the State-of-the Science in Social and Behavioral Intervention?

◆ Although there is no cure yet, persons with autism can make remarkable progress. Interventions early in life may be particularly effective, presumably because of the plasticity of the brain at that time.

◆ Treatment programs that have demonstrated efficacy for young children are characterized by intensity of treatment, low child/adult ratios, and structured and highly-individualized treatment.

◆ People of all ages and ability levels, however, can profit from individualized treatment, and both persons with autism and their families benefit from a lifespan, family approach to treatment.

◆ Treatments that are dramatically effective for one person with autism may be ineffective or even contraindicated for others. Research is needed to identify which treatments are effective for which children or adults over time and which treatment results generalize to different settings or situations.

◆ Too little attention has been given to environments and to the interaction of affected persons with aspects of their environments that typically affect child outcome. Particularly needed are studies of parent-child and sibling-sibling interaction over time, and of the effects of physical environments,

behavioral modeling, relationships, and exposure to speech that could contribute to more or less successful outcomes.

What Major Research Design Change is Needed?

◆Autism is a developmental disorder with very early onset and a chronic life course. Longitudinal research is urgently needed. New statistical methodologies are emerging to make such studies more informative and cost effective.

Author Contact Information:

Marie M. Bristol, Ph.D.
Health Scientist Administrator
Mental Retardation and Developmental Disabilities Branch
Center for Research for Mothers and Children
National Institute of Child Health and Human Development
The National Institutes of Health
6100 Executive Boulevard, Room 4B09 MSC 7510
Bethesda, Maryland 20892
E-mail: BRISTOLM@HD01.NICHD.NIH.GOV

For reprints of the complete report, *State of the Science in Autism: Report of the Autism Working Group to the National Institutes of Health*, write to:

State-of-the-Science in Autism
Office of Research Reporting
Public Information and Communication Branch
NICHD
31 Center Drive MSC 2425
Bldg. 31, Room 2A32
Bethesda, MD 20892-2425

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Ask the Editor

What Is PDD and How Is It Different From Autism?

Fred Volkmar, Associate Editor
Journal of Autism and Developmental Disorders

The term Pervasive Developmental Disorder, commonly abbreviated as PDD, was coined in 1980 as the term for the *class* of disorders to which autism was assigned in the third edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III; APA, 1980). Before 1980 autism was not an official diagnosis in this country but by that time a large body of evidence, much of it published in this Journal, had appeared which suggested the validity of autism as a diagnostic category. Pervasive Developmental Disorder was coined as the term for the overarching class of disorder to which autism was then assigned; the relationship of autism to PDD may best be clarified with a simple analogy: autism is to pervasive developmental disorder as apple is to fruit.

The term PDD has continued to be used in subsequent editions of DSM and now has been included in the International Classification of Diseases as well. In addition to autism several other disorders have been included in the PDD class; at present in DSM-IV (APA, 1994) these include Rett's disorder, Childhood Disintegrative Disorder, Asperger's disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS).

Confusion about the term PDD stems from two major sources. On the one hand there is some disagreement about how appropriate this term was in the first place. On the other hand many individuals use PDD as a shorthand way of referring to PDD-NOS. The question of how appropriate PDD was as a term for the class of disorders to which autism belongs has been debated. (Gillberg, 1991; Happe & Frith, 1991; Volkmar & Cohen, 1991) but it is clear that, by now, the term has assumed a life of its own and will likely continue to be used in the foreseeable future. It has the advantage of suggesting that in autism and related conditions problems are exhibited in multiple areas; it has the disadvantage of seeming to suggest to some that the problems must be exhibited in every area.

The term PDD-NOS is actually the source of rather more confusion. This term is included in DSM-IV since many children exhibit problems in multiple areas suggestive of autism but do not meet the formal requirements for a diagnosis of autism or another explicitly defined PDD. Such so-called "subthreshold" conditions are included in the various classes of disorder in DSM-IV since it is often the case that individuals may have significant problems which do not precisely fit currently recognized, and explicitly defined, diagnostic concepts. The term PDD is often used to refer to PDD-NOS. Sometimes clinicians indeed report that a child "meets criteria for PDD-NOS" when, in fact, the definition of PDD-NOS is, essentially, a negative one without formal diagnostic criteria.

Somewhat paradoxically information on PDD-NOS is relatively limited. This partially reflects the continuing debate about the best approaches to the diagnosis of conditions that appear to be related to autism as well as the difficulties obtaining research support for a very poorly defined condition. This condition is, however, probably much more common than the strictly defined autism, requires rather similar kinds of treatment, and may, depending on associated developmental problems, have a better outcome than autism (Towbin, 1994).

Additional sources of confusion arise because sometimes clinicians assume that PDD-NOS is the same as Asperger's disorder. Although the issue of continuities of all these

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conditions with each other remain an important topic for research, Asperger's disorder is presently explicitly defined to encompass, essentially, children who exhibit the social deficits in autism but have preservation of language and cognitive skills, at least early in life. In our experience (Klin, Volkmar, Sparrow, Cicchetti, & Rourke, 1995), and consistent with Asperger's original paper it is usually the case that children with Asperger's disorder also exhibit remarkable circumscribed interests which they pursue with great intensity and to the detriment of other areas of their development; motor delays and clumsiness are also frequently observed in this condition.

A final source of confusion comes from a seemingly minor wording change in the "nondefinition" definition of PDD-NOS in DSM-IV. Prior to DSM-IV problems in social interaction and communication or unusual behaviors of the type suggestive of autism were required; in DSM-IV this requirement was changed in the final editing process so that problems in only one area are required. This has meant that many less experienced clinicians have come to use the term PDD-NOS in an even broader and probably even less meaningful way.

Interest in research on PDD-NOS seems to be increasing (Van der Gaag, et al., 1995) and it is likely that more, and better, information on this condition and its relationship to more strictly defined autism will be available in the relatively near future.

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Considerations for Intervention and Education

"Considerations for Administrators in the Design of Service Options for Young Children With Autism and Their Families" 45
(Strain, Wolery, & Izeman, 1998)

"Guidelines for Evaluating Intervention Programs for Children With Autism" 55
(Freeman, 1997)

"Report on Autism Conference Sponsored by NEC*TAS" 67
(Federation for Children with Special Needs, 1996)

"One Mother's Reflections: Recent Reading About Autism" 71
(Federation for Children with Special Needs, 1999)

CONSIDERATIONS FOR ADMINISTRATORS IN THE DESIGN OF SERVICE OPTIONS FOR YOUNG CHILDREN WITH AUTISM AND THEIR FAMILIES

Young children with autism have always presented multiple challenges to administrators and teachers in planning and delivering appropriate services. In recent years, however, the challenge to publicly supported service delivery under IDEA has become highly litigious. In the past two years, for example, more than two dozen hearing officers or federal judges have decided that IEPs (individualized education programs) for specific children with autism were not designed in such a way as to achieve reasonable educational benefit. In this highly emotional and confrontational atmosphere, administrators who are charged with the general allocation of resources that can be brought to bear in any IEP process require the best available information for decision making.

The goal of this article is to provide, as we best know it, that information. In the following section, four straightforward assumptions are proposed to stimulate thinking about general intervention planning. We follow this section with a brief review of promising practices for young children with autism, and finally, some cautionary comments.

Assumptions About Young Children With Autism

The first assumption is that *children with autism are children.* Although they have unique behavior patterns and characteristics, they share many behavior patterns with other children, including those with and without disabilities. Also, there are few, if any, autism-specific educational practices (i.e., practices that are effective with all children who have autism and only with children who have autism). Thus, much of what we have learned from other children may be applicable to children with autism. Children with autism also share another vital characteristic with other children: they have a right to the highest quality education and care available.

We have learned many factors influence children's development

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Phillip S. Strain, Ph.D., University of Colorado, Denver
Mark Wolery, Ph.D., University of North Carolina, Chapel Hill
Sue Izeman, Ph.D., Private Consultant, Pittsburgh, Pennsylvania

(e.g., their genetic inheritance, their biological and physiological functioning, etc.), but children's observations of the physical and social phenomena in their worlds, and their interactions with the physical and social dimensions of their worlds, are critical factors (Lamb, Ketterlinus, & Fracasso, 1992). Our programs are organized attempts to increase the likelihood that children will have the interactions and observations that promote learning of adaptive and desirable behaviors (Wolery & Sainato, 1996). We must realize all interactions and observations children have may influence their development, including those interactions we plan and those that occur outside our intervention efforts. Some interactions and observations, however, are more important than others. Important ones include those based on a child's attention, those that are self-directed, and those that are goal-directed (McWilliam & Bailey, 1992). Such interactions are likely to result in more learning than those directed by others and not based on children's attention.

Thus, children's behaviors are critical determinants of our instructional exchanges. We must, therefore, be good observers of children's behaviors, interpret their behaviors as intentional, and respond to those behaviors in flexible and contingent ways (Dunst, Lowe, & Bartholomew, 1990). We need a balance between responsive teaching and directive teaching; a balance between following a child's lead and ensuring the child responds to specific events; a balance between self-directed learning and following the agenda of adults. Either curricular extreme (i.e., totally responsive or totally directive) is likely to produce restricted outcomes.

We also know that children must learn to apply (i.e., generalize) skills they have acquired when and wherever those skills are needed. Practices that have been effective in promoting generalization include using natural contingencies, teaching in generalization environments, teaching behaviors that are needed and supported in generalization situations, using general case instruction, and using self-control techniques. More information on these practices can be found in Horner, Dunlap, and Koegel (1988).

Second, we can assume *children with autism grow up*. As early childhood educators, we frequently do not attend to the fact that in a few short years the children will be young adults. Given this fact, we must select what we teach carefully. Three models have been used to select what we teach: (1) developmental milestone approach, (2) developmental theory-based approach, and (3) the functional approach (Bailey & Wolery, 1992; Dunst, 1981).

Children with autism are children.... We can assume children with autism grow up.... We can assume children with autism have families.

The developmental milestone approach is not useful in determining what to teach; however, the developmental theory-based and functional approaches are. The developmental theory-based approach involves constructivist perspectives (e.g., Piaget, Vygotsky, etc.), and the functional approach involves behavior or ecological perspectives. These approaches can be used together to determine what to teach most young children with autism. It is important, however, that we select the targets of our instruction from a longitudinal perspective; that is, the skills we teach should help children become more competent and independent adults (Wolery, 1996). This is not to suggest, however, that children with autism become the victims of overly prescriptive interventions that may unintentionally result in foreclosing typical childhood opportunities for fun, play, and exploration.

Third, we can assume *children with autism have families*. In the last ten to 15 years, we have learned a great deal about how to support families of young children with disabilities. We now recognize: (1) our services for families must be individualized, just as our services for children are individualized; (2) our approach to families must be based upon and embedded in an ongoing relationship with them; (3) their definitions of goals and priorities are important factors in determining what services should be provided; (4) we cannot ignore their perspectives of their children;

(5) the other demands on their time and effort are important considerations in planning instructional programs; (6) converting them into "therapists" may not do them a long-term service, although there is little as empowering as being able to change the behavior of children when necessary; (7) our goals are to assist them in becoming independent and becoming problem solvers related to their children; and (8) the informal assistance they receive from friends, their own families, and from others is a critical support we should not supplant (Bailey, 1994; Dunst, Trivette, & Jodry, 1997; Vincent & McLean, 1996). Thus, one of the primary goals of intervention is to provide support to families of children with autism. In terms of instruction, we also must recognize that parents should be involved intimately in selecting what to teach, in deciding when and where instruction should be provided, and in making decisions about their role in instructional activities (Wolery, 1996).

Fourth, we can assume *children with autism live in communities.* It is in society's interest for individuals with autism to spend their lives in the community with appropriate supports. To increase the probability that this outcome will occur, the curriculum (even at the early childhood level) should be community-referenced. If the family asks for assistance related to helping the child function in the community (e.g., at a babysitter's home; at the local church, synagogue, or mosque; at the swimming pool; at the grocery store), then the early intervention personnel must be responsive to such requests. In addition, any group care and education for toddlers and preschoolers with autism should occur in integrated settings. The goals of integrated programs are: (1) to provide competent communicative partners, (2) to provide competent social interactive and play partners, (3) to provide competent models of adaptive behavior for imitation, (4) to provide opportunities for friendship formation and social relationships, and (5) to diminish stigma and stereotypes while promoting positive attitudes and actions toward persons with disabilities (Wolery & Wilbers, 1994).

... [S]imply being in an integrated program is not sufficient for young children with autism; those programs must be vital learning environments.

However, simply being in an integrated program is not sufficient for young children with autism; those programs must be vital learning environments. At a minimum, integrated programs should be characterized by the following: (1) the staff receives ongoing training; (2) the staff receives ongoing support; (3) specialized service providers (e.g., early childhood special educators, speech-language pathologists, psychologists, etc.) are available on an ongoing basis; (4) instruction on goals is planned and embedded into ongoing activities and routines; (5) the implementation of the instruction and its effects is monitored continuously and used to adjust that instruction as needed; (6) social interactions and relationships, social play, peer imitation, and language and communicative behavior are programmed purposefully and intensely; (7) behavior challenges are addressed; and (8) the activities and curriculum for typically developing children are of the highest quality (Hoyson, Jamieson, & Strain, 1984; Peck, Odom, & Bricker, 1993). Without these characteristics, integrated programs for children with autism are no more defensible than segregated programs.

Promising Practices

There are many specific, empirically-supported models of service delivery as designed by Fox, Dunlap, and Philbrick (in press); Harris and Handleman (1993); Lovaas (1987); Strain and Cordisco (1993); McClannahan and Krantz (1993); and McGee, Daly, and Jacobs (1993). While these models differ widely in philosophy and practice, they do share a number of very critical dimensions. It is these shared dimensions that can provide program planning guidance to administrative personnel, particularly when there is direct evidence linking a particular intervention strategy to a certain set of child outcomes. The promising practices are as follows:

1. **Young children with autism should be provided with regular and planned opportunities to interact with typical age-peers.** While many young children with autism are not served in inclusive settings, it is becoming increasingly clear integrated service options are essential to optimizing outcomes. Yet, as detailed by Strain (1991), quality inclusion implies far more than a placement decision. To achieve the potential of inclusive programming, service delivery must not compromise on the level, range, or nature of intervention available to children and families.

   ... [Q]uality inclusion implies far more than a placement decision.

   In the largest, ongoing longitudinal study conducted to date on inclusive early intervention for children with autism, all 51 children studied were integrated successfully with typical preschool classmates (Strain & Cordisco, 1993). This study is of particular significance because children with autism were enrolled without regard to their level of severity. Supplementing this long-term follow-up study are a host of other studies (e.g., Goldstein & Kaczmarek, 1992; Hecimovic, Fox, Shores, & Strain, 1985; Kohler, Strain, & Shearer, 1992; McGee, Paradis, & Feldman, 1993; Odom & Strain, 1986; Strain, 1984; Strain & Fox, 1982; Strain, Hoyson & Jamieson, 1985; Strain & Odom, 1986) showing that:

   - Typical age-peers can be taught easily to facilitate the social and communicative abilities of their classmates with autism.
   - Simply being in physical proximity to typical peers reduces the level of "autistic-like" behaviors observed in some young children with autism.
   - Developmentally segregated settings can have a "toxic" effect on the generalization and maintenance of newly acquired skills.

   In many cases, this promising practice will require the expansion of high-quality integrated service options for young children with autism.

2. **Teaching for young children with autism should be carefully planned, executed, and evaluated.** Many young children with autism display learning characteristics that pose great challenges. For example, chil-

dren may appear to be competent on a particular task one day and the next day they behave as if they have no idea what to do. Generally speaking, great variability in performance is one of the most frequent challenges faced by service providers. If we are to begin to understand and eventually reduce this variability, it is essential to plan, deliver, and evaluate precisely the instruction provided.

Today, there is a well-established "technology" of teaching young children with complex learning needs, including those with autism (Bondy & Frost, 1993; Harris & Handleman, 1993; Koegel & Koegel, 1995; Lovaas, 1987; McClannahan & Krantz, 1993; McGee, Daly, & Jacobs, 1993). The specific features of this technology, to be applied in home, community, and school settings include:

- Task analyzing skills to teach
- Selecting motivational incentives for specific children
- Incorporating instructional goals within daily routines and activities
- Ensuring an adequate intensity and quality of instruction

These teaching methods do not simply result in quality child outcomes, they also afford a clear mechanism by which programs can ensure effective practices.

3. **Young children with autism and their families require a level of intervention to match their individual needs.** Today, there is considerable debate and controversy about what constitutes an early intervention approach of sufficient intensity. Often the question of intensity becomes translated into overly simplistic notions that imply children with autism require a certain number of hours of daily instruction or therapies. When studying intensity, ensuring the treatments are comparable and differ only in the dimension of intensity is nearly impossible, and existing research can be questioned on this and other issues. Thus, to help guide decision making on the question of intensity we are left with an analysis of program intensity characteristic of early intervention models of demonstrable effectiveness. From such an analysis we can conclude that all current school-based programs for preschool-age children that report efficacy data on service delivery components or the entire model share these characteristics (Anderson, Campbell, & Cannon, 1993; Bondy & Frost, 1993; Harris & Handleman, McClannahan & Krantz, 1993; McGee, Daly, & Jacobs, 1993; Strain & Cordisco, 1993):

   - Services are provided year-round, allowing, of course, for staff and family vacations.
   - In-class services range from three to six hours, five days per week.
   - Total intervention services, including in-class time and time spent at home and in community settings, range between four to six hours, five to seven days per week.

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Within the range of intensity across effective models there is little evidence that more is better. Certainly, intervention must occur at some level, but the quality of the instructional exchanges, the competence of teachers, and the degree of continuity across teachers and settings may be more important than the total number of hours. Relatedly, there is no evidence a particular child to staff ratio is critical (child to staff ratios range from 1:1 to 3:1) across effective programs. The skill of the adults who deliver the instruction may be a much more important variable than the number of children under their supervision.

The diversity of need within the group of children identified as having autism is too great not to offer a wide variety of service options that vary on many dimensions, including intensity.

4. **Young children with autism and their families require services delivered across many different contexts.** A highly related issue to that of intensity is the location(s) of service delivery. For young children with autism and their families, it seems clear service delivery must consider all environmental opportunities for learning.

The diversity of need within the group of children identified as having autism is too great not to offer a wide variety of service options that vary on many dimensions, including intensity.

Not only do children with autism display many learning needs and challenging behaviors across multiple environments, but they also tend not to generalize skills from one setting to another (Schreibman, 1988). Moreover, for children below 30 months there may be legitimate concerns about the developmental appropriateness of center-based services.

In examining the research on how effective programs have met this challenge of multiple setting needs (Anderson, Campbell, & Cannon, 1993; Lovaas, 1987; McClannahan & Krantz, 1993; McGee, Daly, & Jacobs, 1993; Strain & Cordisco, 1993), several common tactics emerge, including:

- Planning, in the context of the IFSP (individualized family service plan) or the IEP, for what might be described as a "waking hour" intervention strategy. This family-driven process essentially asks caregivers to identify all situations and contexts (e.g., waking up, getting dressed, feeding, riding in the car, shopping, bedtime) that are of some concern, and then helping caregivers use effective instructional practices and exchanges in these contexts.
- Allocating personnel resources such that intervention is provided across many different settings.
- Teaching significant others (e.g., parents, siblings, child care workers, extended family members, babysitters) to employ specific teaching strategies.
- Writing performance criteria to include specific evidence of skill generalization to other settings.

This promising practice may result in a major rethinking of where intervention takes place, who provides it, and the objectives of intervention.

5. **Young children with autism should be provided with a scope and sequence of instruction that covers all areas of developmental needs.** While this standard of excellence may seem patently obvious to many, it is included here because of existing "folklore" regarding the curative powers of various therapies. That is, some have suggested that communication treatment X, or motor treatment Y, or sensory treatment Z may affect the overall development of young children with autism. We can not find credible scientific evidence to indicate that any singular modality of intervention produces a broad, generalized impact on young children with autism. On the contrary, there is overwhelming evidence to suggest such sweeping effects from sin-

gle modality therapy do not occur (Schreibman, 1988).

In examining the research on how empirically-validated early intervention models have addressed the multiple and diverse needs of this population (Anderson, Campbell, & Cannon, 1993; McGee, Daly, & Jacobs, 1993; Strain & Cordisco, 1993), the following practices emerge:

- The adoption and combination of many different early childhood and early childhood special education curricula to yield the maximum depth and breadth of instructional objectives.
- Utilization of multiple integrated therapy modalities.
- Conducting multiple IEP or IFSP evaluations during the year to ensure adequate teaching coverage to achieve objectives.
- Teaching across multiple intervention agents and settings.

The best safeguard against too narrow intervention options is a sound multidisciplinary planning process.

The best safeguard against too narrow intervention options is a sound multidisciplinary planning process.

6. **Young children with autism should be enrolled in intervention services as early as possible.** While this standard is by no means novel in the early intervention field, there may be a particular incentive to expedite the earliest possible enrollment of young children with autism. While there is not a direct, unambiguous scientific test of the age-at-start issue for children with autism, the profession seems to be headed toward a consensus on this issue in light of the early enrollment of children in several of the more effective model programs (Lovaas, 1987; McClannahan & Krantz, 1993).

   In reviewing exactly how these and other programs facilitated early and timely referrals, several common tactics emerge, including:

   - Establishing a strong liaison with medical community personnel, emphasizing the availability of services.
   - Distributing awareness information in the community regarding the early indicators of autism and referral sources.
   - Initiating local media (e.g., newspapers, public service announcements) coverage regarding the essential nature of early referral and intervention.

   This promising practice may well dictate a reallocation of assessment and screening resources such that timely identification and programming occur.

7. **The challenging behavior of young children with autism should be addressed with positive, proactive strategies.** Young children with autism often exhibit a wide variety of disruptive, stereotypic, aggressive, and/or challenging behaviors. Considerable debate exists about the efficacy and ethics of using aversive interventions. For young children with autism, however, current research strongly supports the use of preventive and positive strategies for reducing the occurrences of these behaviors (Koegel, Koegel, & Dunlap, 1996). Specific strategies include:

   - Environmental rearrangement and schedule changes to include more play materials and play space.
   - Increasing children's engagement with activities and materials (and conversely decreasing their disruptive behavior) by identifying preferred materials and activities; systematic use of preferred toys and materials; redirecting children to preferred activities; and providing children with choices of activities and reinforcers.
   - Functional analysis of children's behaviors and teaching children social and communicative skills to take the place of disruptive behaviors.
   - Incorporating natural teaching strategies (e.g., functional materials, natural rein-

forcers, teaching within a natural interaction) into instruction.

In many cases, the lens used to analyze challenging behaviors is too narrow. More resources should be focused on changing instructional environments rather than on making the behaviors stop.

In many cases, the lens used to analyze challenging behaviors is too narrow. More resources should be focused on changing instructional environments rather than on making the behaviors stop.

Cautionary Comments

Early intervention for young children with autism is, relatively speaking, a youthful field of endeavor. In such a field of rapidly expanding knowledge, it is the fool who insists upon and speaks with absolute certainty. What was considered state of the art in 1980 is now largely a relic of the past. Our prediction is that state of the art in the year 2007 may well look quite different than it does in 1998. Such is the nature of a young field.

Regrettably, it is also in the nature of a young field to suffer from extravagant claims and the zealous marketing of one size fits all models of intervention. We caution the consumer to beware. Not only should specific intervention tactics used in any model be effective as demonstrated by accepted scientific practices, but consumers must consider and question more carefully, including: (1) efficiency of the strategy in yielding a socially significant level of outcome for a reasonable level of effort, time, and expense; (2) fit of the strategy with state and local values and culture; (3) whether the strategy is as normalized as possible; (4) whether the strategy is developmentally and individually appropriate; (5) whether the strategy is respectful of and accommodates variations in family needs, values, resources, and desires; (6) whether children look as if they are having fun (e.g., are easily engaged as compared to resistant) when they are involved in the strategy; and (7) how the strategy is consistent or inconsistent with the Division for Early Childhood's Recommended Practices.

Although we have much to learn about providing effective and efficient services to young children with autism and their families, the field has learned a great deal. Administrators, practitioners, and families do not have to design services for these children in a knowledge vacuum. The promising practices described here are legitimate bases from which to begin allocating resources, acquiring more resources, and planning individualized services for young children with autism, and the sources cited in this article describe those practices in much more detail.

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Guidelines for Evaluating Intervention Programs for Children with Autism

B. J. Freeman[1]

University of California–Los Angeles School of Medicine and Neuropsychiatric Institute

It is now well recognized that early diagnosis and intervention improves the prognosis for children with autism. It is crucial that professionals be aware and sensitive to the needs of autistic persons and their families. We must never lose sight of the long-term goal of treatment and must not become so infatuated with any one treatment that we fail to provide the education parents need. It is incumbent upon us, as professionals, to educate parents and help them evaluate the myriad of information with which they are bombarded. In this article a framework for thinking about autism and principles of evaluation are reviewed. Components of appropriate early intervention programs are then described and guidelines for evaluating alternative treatments are provided.

The purpose of this paper is to provide guidelines for evaluating intervention programs for autistic persons. However, before we can evaluate intervention strategies, it is important to review what we know about autism, as well as what constitutes an adequate evaluation. Evaluation and diagnosis are always important precursors to development of appropriate treatment strategies.

Autism was first described by Kanner (1943) in his now classic paper, "Autistic Disturbances of Affective Contact." Kanner described a unique group of children who had failed to develop normal relationships, were upset by changes in their environments, and showed abnormalities in speech and language. The "autism" or self-centeredness in these children

[1]Address all correspondence to B. J. Freeman, Division of Child and Adolescent Psychiatry, Department of Psychiatry, University of California-Los Angeles School of Medicine and Neuropsychiatric Institute, 760 Westwood Plaza, Los Angeles, California 90024.

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was recognized as the primary deficit and the terms "autistic" and "autism" came to denote their disorder. Similar patterns were soon identified in children throughout the world.

In the 50 years since Kanner's initial paper, children with the syndrome of autism have been labeled as having childhood psychosis, severe emotional disability, atypical ego development, childhood schizophrenia, symbiotic psychosis, early (primary) or late (secondary) onset autism, or mental retardation with autistic features. Fortunately, in the mid-1990s, the situation has improved dramatically. In 1978, the Autism Society of America formulated a "Definition of the Syndrome of Autism" (Ritvo & Freeman, 1978). It represented a consensus among professionals from different countries and disciplines and formed the basis for a definition published in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (APA, 1980, 1987). These diagnostic criteria have been further refined in the latest edition (APA, 1994) to identify subgroups of children with autism.

These current definitions are based on assumptions and facts which may contradict some long-held beliefs about autism and require updated thinking. It is now agreed that:

Autism is a clinical (behaviorally defined) syndrome. This is because objective biomedical markers common to all cases have not yet been identified. Like all syndromes (e.g., pneumonia, epilepsy, hypertension, diabetes), autism is assumed to be composed of many subtypes, each with different etiologies and possible treatments. Anything that can cause damage to the central nervous system could cause damage to the parts of the brain that then produce these behaviors we identify as autistic (Gillberg, 1990; Schopler & Mesibov, 1987).

Autism is a spectrum disorder. The concept of a spectrum or continuum of symptoms is enormously complex. Although the expression of symptoms ranges from severe to mild, the concept of a continuum of symptoms is not simple. The manifestation of social and other impairments vary widely in all combinations of subtype and severity. Although most subtypes have not been named as separate syndromes, some have, such as Rett (Philippart, 1986). The mistake most often made in diagnosis is the failure to recognize all the possible combinations of symptoms that can occur (Volkmar et al., 1994).

Autism is a developmental diagnosis. As with all diagnoses made in childhood, expression of symptoms varies with both the age and developmental level of the person affected. Thus autism is lifelong. Although symptoms fluctuate, abate, change, and some may even disappear; once autistic, always autistic. Autistic persons have a normal life expectancy and the majority require lifelong social support systems due to their developmental handicaps and continuing symptomatology (Dahl, Cohen, & Provence, 1986).

Autism is a retrospective diagnosis. While symptoms can appear as early as the first month of life, some children display normal development until 12–24 months of age. Since most children are not seen until later and some persons are not seen until they are adults, it is not possible to make a differential diagnosis until a careful developmental history is obtained. This history should cover all aspects of development and/or a person's life course (Dahlgren & Gillberg 1989: Vostonis, Smith, Chung, & Corbett, 1994).

Autism is ubiquitous. It occurs in all parts of the world, in all races, and in all types of families. No social or psychological characteristics of parents of families have proven to be associated with autism. Boys are affected more often than girls by a ratio of four or five to one and some families have more than one autistic child (APA, 1994).

Autism frequently occurs in association with other syndromes, specific diseases, and developmental disabilities. The most common co-occurring condition is mental retardation. For example, approximately 50% of all autistic patients also have the syndrome of Mental Retardation (i.e., score below 70 on IQ testing). This is because the brain pathology that produces the symptoms of autism also affects cognitive development and symbol processing (Freeman et al., 1991). Epilepsy, motor incoordination, fragile X, and severe allergies are other frequent concurrent syndromes (Ritvo et al., 1990). As persons with autism develop into adolescence, many become anxious or depressed as a result of social pressures. There is no reason to believe that having autism precludes other forms of psychopathology.

Though there is no known cure, children with autism improve with proper intervention. In the past a diagnosis of autism was considered to be a "death sentence." The assumption was that it was a hopeless condition and children did not get better. It is now recognized that people with autism not only improve but can and do lead happy productive lives with proper intervention (Campbell, Schopler, Cueva, & Hollin, 1996; Powers, 1992).

DIAGNOSIS OF THE SYNDROME

The DSM-IV (APA, 1994) criteria for autism state that in order to make the diagnosis of autism a child must show abnormal development prior to age 3 as manifested by delays or abnormal functioning in social development (i.e., gross and sustained impairment in social interaction), language or its use in social communication or play (i.e., gross and sustained impairment in communication), and restricted patterns of behaviors, interests and activities. Subtypes of autistic disorder, listed as other pervasive developmental disorders, include Rett syndrome, Heller syndrome, Asperger syndrome, atypical autism, and atypical Pervasive Developmental Disorder (PDD).

These diagnostic criteria often result in confusion when applied to preschool-aged children. Terms such as childhood onset PDD and atypical PDD often cloud the diagnostic picture of autism. Dahl et al. (1986) have suggested that the main differences among these groups are degrees of impairment. Thus, it is more useful clinically to consider these different groups along a continuum of autistic disorder rather than as suffering from different conditions requiring different treatments.

Differential and early diagnosis of autism is critical because the prognosis for autistic children has changed markedly since Kanner's (1943) initial work. Identifying and diagnosing autism early can provide access to appropriate services which results in a better prognosis. In addition, parents benefit from having a label to put on their child's problem. It helps them understand why the child is having difficulties and helps to focus treatment efforts (Akerley, 1988). In spite of the recognized advantage of differential diagnosis, there is still sometimes a reluctance among professionals to "label" a child.

Konstantareas (1989) identified several problems around the diagnostic process and reluctance to label a child. These include failure to recognize a full range of the symptoms, reluctance to label a child, attempts to minimize severity of the disorder, inadequate feedback and counseling, and failure to make appropriate recommendations. To avoid these problems the diagnostic process should include a flexible, tolerant, and empathetic attitude toward the child and family. Once the differential diagnosis includes autism, evaluations outlined in Table I must be undertaken to assess organic, cognitive-intellectual, psychological, and family factors. The diagnosis of autism should be based on direct observation of the child in both structured and unstructured situations as well as a careful developmental history. An adequate evaluation always includes a parent education component.

PROGNOSIS OF THE SYNDROME

Several investigators have traced the natural course of the syndrome. Between 7 and 28% of autistic children, who showed no clinical evidence of neurological disease in early childhood, developed seizures by age 18 (Rutter, 1970). Approximately 50% of all autistic persons function in the retarded range throughout life. Initial cognitive test scores are highly predictive of later outcome (Freeman, Ritvo, Needleman, & Yokota, 1985). Children with seizures and other indications of specific organic brain dysfunction tend to be the most retarded, undeveloped, and ultimately impaired.

Table I. Components of Evaluation for Autism

Historical information
Early developmental history
Nature/type of onset
Associated medical problem, family history
Psychological/communication assessments
Verbal and nonverbal skills must be assessed independently
Assessment of social-adaptive behaviors
Communication (not just speech) evaluation
Psychiatric assessment
Nature of social relatedness
Behavioral features
Play skills
Family/living conditions
Medical evaluations/laboratory studies
Associated conditions
Genetic screening
Auditory testing
EEG/MRI/neurological/other consultations as needed

The second prognostic group, approximately 25%, contains children whose motor development is relatively normal and who develop communicative language before age 5. Children in this group usually become extremely shy, introverted, and passive when adolescents. They need continued supervision in living situations, but can often function in supported employment.

The third prognostic group (approximately 25%) have normal intelligence, are able to live and work independently and, in some cases, may marry and have children (Ritvo, Freeman, Mason-Brothers, & Ritvo, 1994). However, these persons continue to show significant personality, social, and specific cognitive impairment. Other recent studies by Freeman et al. (1991) and Venter, Lord, and Schopler (1992) are more optimistic. With increased expansion of social, vocational, and residential support services in the community, persons challenged with autism increasingly are able to maximize their potential.

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DEFINITION OF TREATMENT

Once a child has been diagnosed with autism the most often asked question by parents is, "What do I do now?" It is important to remember that children with autism are individuals. As a result, a wide variety of treatment approaches may be necessary. Treatment programs should never lose site of the long-term goal which is to improve the outcome for persons with autism. Outcome is defined by quality of life indicators, that is, empowerment to live, work, learn, be mobile, and have fun in settings where everyone else does these activities, in natural settings with family, friends, and coworkers. Any evaluation of a treatment program must focus on outcome and not program specifics.

Powers (1992) has identified the components of best teaching practice for children with autism. These include structured treatment utilizing the principles of applied behavior analysis; parent involvement in home, school, and community; early intervention; intensive treatment, programming for generalization; curricula that emphasize development of social and communication skills; and integration with typical peers when possible. Powers goes on to review various early intervention programs and concludes that there are ample data to support the conclusion that early intervention works with young autistic children. However, we need many more data before we can conclude that any one program is appropriate for every child.

EVALUATING PROGRAMS

In the past there have been many proposed "cures" for autism. These have ranged from psychodynamic psychotherapy to operant conditioning (Lovaas, 1987). Currently, we do not know the etiology of autism and cannot cure it. Autism is a neurological problem that affects the way the brain processes information. Persons with autism who have the best outcomes (as defined above) are those that know they have autism and understand what that means (i.e., "my brain works differently").

Although many treatments have been proposed, there is only one treatment that has passed the test of time and is effective for all children, autistic or normal, that is, *structured educational programs geared to the person's developmental level of functioning.* Other treatments might be helpful at different points in an autistic person's life. It is important to keep an open mind and educate ourselves regarding new treatments as they become available. However, the majority of *other* treatments proposed for autistic people have yet to be proven scientifically (Campbell

Table II. Guidelines for Evaluating Treatments for Autism

1. Approach any new treatment with hopeful skepticism. Remember the goal of any treatment should be to help the person with autism become a fully functioning member of society.
2. *Beware* of any program or techniques that is said to be appropriate for every person with autism.
3. *Beware* of any program that thwarts individualization and potentially results in harmful program decisions.
4. *Be aware* that any treatment represents one of several options for a person with autism.
5. *Be aware* that treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child.
6. *Be aware* that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it will be appropriate for an individual with autism.
7. *Be aware* that debate over use of various techniques are often reduced to superficial arguments over who is *right, moral, ethical and who is a true advocate for the children*. This can lead to results that are directly opposite to those intended including impediments to maximizing programs.
8. *Be aware* that often new treatments have not been validated scientifically.

et al., 1996). It is imperative that parents and professionals educate themselves before making a treatment decision, remembering that what is right for one child may not be right for another. Treatment decisions should always be made individually after an assessment and based on what is appropriate for that particular child and family at that point in time. Periodic reevaluation is mandatory as needs change as a person with autism develops and matures.

Table II shows some general guidelines for evaluating various treatment procedures. The most important thing to remember when attempting to evaluate any treatment program is that every child with autism is an individual and what is appropriate for one child may or may not be appropriate for another. However we must approach any new treatment with hopeful skepticism. As yet, we do not know the specific cause of autism and therefore cannot cure it. The goal of any treatment must be to help a person with autism become a fully functioning member of society. Any treatment approach that does not aid in this long-term goal is not appropriate.

In addition, we must always *beware* of any program that claims to be appropriate for every individual with autism. Autism is a heterogeneous disorder and presents in many forms. Therefore, what may be appropriate for one autistic child at a given time may not be appropriate for another child or for the same child at a different time.

As noted, each person with autism is a unique individual. As a result we must *beware* of programs that do not consider this factor. This can often result in harmful programming decisions. The usefulness of a particular program or treatment must be evaluated for each autistic person individually. Periodic reassessments of a treatment plan need to be made to assure that individual needs are continuing to be met as the person with autism matures. Failure to consider each person as an individual can result in not providing that opportunity to learn the skills necessary to function in society.

We must always be aware that as yet no one has the "magic bullet" that cures autism. Therefore, any treatment approach must be viewed as one of several options available. It is important to evaluate the pros and cons of each approach and examine how it would facilitate reaching the long-term goal of independent functioning. While each new treatment may represent one of several options for persons with autism, only one treatment has stood the test of time and has been shown to be effective for every autistic person, that is, structural educational programs geared to developmental level of functioning and teaches functional social skills (Campbell et al., 1996).

Since autism is a heterogeneous disorder with multiple etiologies, alternative treatments may prove helpful for some children at various points in their lives. However, no new treatment should be implemented until assessment procedures necessary to determine whether it is appropriate have been specified. All too often, proponents of alternative treatments advocate that every child with autism should have a given treatment. As a result, the debate over uses of various techniques is often reduced to superficial arguments over who is right, moral, and ethical, and who is the true advocate for the child. This often lead to controversy and to results opposite to those intended (i.e., maximizing a child's potential). Finally, it is important to realize that some treatments have not been validated scientifically. The scientific method involves conducting objective studies which are published in peer-reviewed journals. Many advocates of alternative treatments for autism rely on anecdotal information to support their position that every child have the treatment.

Once we have considered these principles for evaluating alternative treatments, it is important to ask the following five questions, listed in Table III:

Table III. Questions to Ask Regarding Specific Treatment

1. Will the treatment result in harm to the child?
2. Is the treatment developmentally appropriate for the child?
3. How will failure of the treatment affect my child and family?
4. Has the treatment been validated scientifically?
5. How will the treatment be integrated in to the child's current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life, and social skills are ignored.

Will the treatment result in harm to the child? This may seem obvious but harm to a child is not only physical. Harm can also result form failure to provide exposure to the program that would maximize potential.

Is the treatment developmentally appropriate for the child? It is critical that a child's developmental level be factored into any treatment plan. We must be sure that we are not demanding that the child with autism do things that we would ask a typical child to do. We must also examine what is appropriate across the life-span as a person with autism develops. What is appropriate at age 2 years is not an appropriate intervention at age 18.

How will failure of the treatment affect my child and family? Often times families spend all their resources in search of the "magic bullet." As is inevitable, when their child is not "cured" and their financial and emotional resources are spent, families are often in crisis. It is important to view autism as a family problem and to integrate the child into the family. Autism must be viewed as a lifelong problem. If all resources whether emotional or financial are exhausted when a child is young, families are not able to cope as the child grows older.

Has the treatment been validated scientifically? This may not be an important consideration for some families. However, it is crucial that parents and professionals be aware of the scientific validity of particular treatments. Some families may want to try out experimental treatments. If so, it is incumbent upon us as professionals to educate them regarding its scientific validity. Often people expect the miracle and we as profcssionals must always temper these expectations.

How will the treatment be integrated into the child's current program? This is perhaps the most important question. We must not become so infatuated with new unproven treatments that we fail to provide appropriate intervention (i.e., individual structured educational programs geared to developmental level of functioning). There is now ample evidence (Campbell et al., 1996) that when intervention focuses on functional, vocational, and life skills, persons with autism improve.

CONCLUSION

It is now well recognized that early diagnosis and intervention is important to improve the prognosis for children with autism. It is crucial that professionals be aware and sensitive to the needs of autistic persons and their families. We must never lose sight of what the long-term goal of any treatment is and must not become infatuated with any one treatment that we fail to provide the education parents need. It is incumbent upon us, as professionals, to educate parents and help them evaluate the myriad of information with which they are bombarded. In this article, I have attempted to provide a framework within which to think about autism and guidelines for evaluating various treatment options.

What does the future hold? In the absence of etiologically based treatment we need to improve the quality of life of autistic persons by providing increased opportunities to be integrated into society. Specifically, we need increased vocational training and opportunities, increased independent living skills programs and alternative transitional programs across the life-span; increased social support programs and social skills training, and, finally, increased public education and awareness of the unique abilities by persons challenged by autism.

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News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

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REPORT ON AUTISM CONFERENCE
*Sponsored by NEC*TAS*

This issue of **Early Childhood Bulletin** *is a summary update on programs for young children with autism. The article has been written by Martha Ziegler, parent of an adult daughter with autism and project director of the parent component of NEC*TAS (National Early Childhood Technical Assistance System), located at the Federation for Children with Special Needs in Boston. While some of the comments here stem from Ziegler's years of experience as a parent and advocate, most of the information was presented at a conference on autism for interested Part H and Section 619 state program coordinators and Interagency Coordinating Council (ICC) parents of children with autism. The conference was held in Hartford, Connecticut, in February 1996.*

It is gratifying to find so much interest in autism among Part H and Section 619 Program Coordinators. This recent surge of interest bodes well both for parents and for young children with autism. It seems to indicate that children are being identified at an earlier age than had been occurring and in addition, more are being referred for early intervention and preschool programs.

Also encouraging is the fact that the federal programs for early childhood special education may well offer the solution that has been so badly needed in the field of autism for many years: namely, the integration of fragmentary and isolated approaches to the education of children with autism.

A major reason for the nationwide interest in autism by early childhood educators is the current (or recurrent?) controversy around some of the interventions being recommended, especially 'discrete trial' methodology, or the Lovaas approach as it is sometimes referred to. Over the last 25 or 30 years, autism has been plagued with one 'magic cure' after another. Often each new therapy offers some actual help but never the cure that has been promised.

A recent conference sponsored by NEC*TAS brought together Part H and Section 619 Program coordinators, individual program providers, and Interagency Coordinating Council (ICC) parents of children with autism. The single overriding theme that emerged from the proceedings was the importance of family support, in a variety of forms. In the opening panel, parents spoke about this need; they all talked about the impact of the disability on the whole family and about the need for support and assistance. One parent said 'Who most needed help was ME!' A father said that he and his wife had needed a 'family advocate,' and they benefited greatly from opportunities to network with other families. A third panelist, who is both a parent and a professional, talked about the importance of training in the home. A fourth panelist discussed the importance of effective communication with the professionals who are working with her son and the importance of her own validation by these professionals.

Several program providers began their presentations by saying that their highest priority also is family support. That term varied some in precise meaning, but the universal awareness of need was impressive. Forms of support ranged from parent training to in-school respite care, a program for keeping children occupied during school vacations.

Parents at the conference all agreed that one of the

hardest challenges they face is choosing which method of intervention to try. Dr. Susan Izeman, from the Pennsylvania Department of Education, presented the following 'Points to Ponder,' a list of questions to be considered by both parents and providers in assessing the various options for intervention:

1. What are the anticipated outcomes of this intervention?
   What positive changes can I expect to see in my child's behavior, communication, eating, sleeping, learning, etc.?
   Do these outcomes address what I see as an area of need for my child?
   Do these outcomes match my expectations or goals for my child?
   Are there any potentially negative outcomes of the intervention?
2. How will this be evaluated?
   How will I know if my child is making progress toward desired outcomes?
   What method will be used to evaluate child progress?
   How often will we evaluate child progress?
   Who will conduct the evaluation?
   How long will we continue until a change can be made in the intervention?
3. What are the potential risks?
   Will my child face any immediate risk?
   Are there any risks for other family members?
   Are there any activities, foods, etc. that will be restricted?
4. What is the back-up plan if we choose to discontinue this intervention?
   Is there any risk of discontinuing the intervention?
   What kind of early intervention services will my child receive if we decide to stop the intervention?
5. Is there a good fit between the intervention and our family life?
   Can we do what will be asked of us?
6. Have I gotten information about this from a variety of sources?
7. Is this intervention published in peer-reviewed journals?
8. Are there alternatives that are:
   less restrictive?
   better researched?
9. How will this new intervention be combined with strategies and therapies that we are already using with my child?

(Dr. Izeman has acknowledged contributions to her work from Dr. Phillip Strain, University of Colorado; Lori Mousetis, Coordinator of Speech Services, Project DART, Allegheny Intermediate Unit, Pittsburgh; and the staff of the LEAP Preschool, an integrated preschool associated with the D. T. Watson School, Pittsburgh.)

Parents may want to add other questions to this list. Dr. Izeman has suggested that a "Yes" or "No" to any one question should not mean an automatic acceptance or rejection of a particular method. Rather, she suggests that the questions be taken as a whole, as a guide to seeking information.

Another theme that permeated the meeting was the great variation among individual children within the overall category of autism. This theme began with the discussion of labels: autism, PDD (pervasive developmental disorder), Asperger's Syndrome, and others. Most experts seem to agree that all these terms are really aspects of autism and that they simply confirm the importance of recognizing the individuality of children with autism.

Mark Greenstein, a pediatrician and geneticist from Connecticut, talked about the three fundamental domains of dysfunction that characterize autism and the varying degrees of severity that can occur in any of the three: social behaviors, communication (verbal and nonverbal), and interests and attention. Greenstein, along with several other speakers, emphasized the fact that all behavior in autistic children is communicative. Greenstein and others have explained that children and adults with autism become more and more frustrated and anxious when either (1) they are misunderstood or (2) they misunderstand others, and that the frustration and anxiety often get acted out with what appears to be random aggressive behavior.

Greenstein explained some of the strange habits of autistic children by observing that their linguistic concept of time is gone, that they live in a "perpetual present." Change of many kinds produces consuming fear for them, for they have great problems with adaptation. (During my daughter's early childhood years she would be obsessive about toys, while never playing with them in a developmentally appropriate way. When the gingerbread boy would begin to wear out, I would rush to the store to buy a new one, hoping that she would not notice the difference. If the gingerbread boy was not immediately available, in the washing machine for instance, she would cry inconsolably. Panic set in

when the stores suddenly stopped carrying the gingerbread boy and desperate, I went to a fabric store, bought similar material, and made "new skin" for him.)

Greenstein reported that the incidence of autism has increased markedly on the East Coast during the last seven years and that it is starting to rise on the West Coast as well; he anticipates that the Midwest will eventually follow. He said that the incidence of autism is now the same as Down syndrome: 1.5 per 1,000. No one is certain about the reason for this increase; it may be a result of improved diagnosis, it may be caused by something new in the environment, or it may have some other cause.

During informal networking, parents compared notes about a variety of techniques, especially the use of prescription drugs for their children. They described positive experiences from Prozac, Zoloft, Depakote, and others, often in combination with other drugs. At this conference, as at other conferences, parents indicated that the best results occurred when their children received several different kinds of intervention, such as medication, sensory integration, behavior modification, speech and language therapy, and at least some inclusion with nondisabled peers.

The latest literature on autism, including the books listed below, contains evidence that supports this multiple approach to education and intervention. There can be no doubt that the child with autism has difficulty processing sensory information, and that difficulty may take differing forms. Sometimes the problem and the solution can be amazingly simple: For example, recently my daughter, who lives and works semi-independently, became totally confused about a new job that she expected to undertake. After she walked to the wrong bakery on the wrong day, I finally realized that she had misunderstood what her job coach had told her, almost certainly because the job coach had talked too fast! Over the years I have learned that when my daughter does not fully understand what she is being told, she will do what we all do, that is, guess, based on the context. Unfortunately, because of her disability she often guesses wrong.

Some of the problems confronting autism are no different from those of early intervention in general: a need for more and better research on program effectiveness so that decision making can be research based, for example. Another example is the overriding importance of family support. What does seem to separate autism from other developmental disabilities is the regularity of seductive 'cures' that keep emerging: from megavitamin therapy to strict behavior modification. Often they arise outside the traditions of education or early intervention and frequently they overlook the fundamental needs of the children as children.

Staff development, training of all staff working with the autistic child, was another need that was strongly expressed by conference participants. Professional providers as well as parents need information and training.

One speaker emphasized the importance of a developmental approach to working with children with autism. The speaker suggested periodically posing the following questions: What do most children at this developmental stage do? What do any children need at this age? This approach can be especially difficult for parents, particularly those whose autistic child is the first-born. These parents may have little or no experience to draw upon. (As a parent, I had this difficulty myself.)

Similarly, in choosing an intervention approach, parents and providers should be careful not to make compliance with adults a goal in itself. Past uses of behavior modification techniques often made this mistake. Such an approach can be self defeating. The child's behavior may become more socially acceptable, but this result occurs at the expense of autonomy and self reliance, characteristics that become more and more important as the child grows.

In a discussion about the so-called Lovaas method, one participant made the following point: 'Look at Lovaas' contributions to autism. He has shown that kids with autism can learn and that early intervention and intensity of service are important; further, he has gotten the attention of policy makers.'

As indicated above, one of the most critical needs emerging from the conference is the need for research, especially around outcomes and efficacy. Following are some of the key questions that were posed for researchers:

- Is there a correlation between family support and positive outcomes?
- What are the long-term outcomes of discrete trial intervention (E.g., role, speech, aggression, learning)?
- How will outcomes be different with different interventions?

Questions about research frequently accompanied questions about costs. One speaker made the important point that programs for children with autism are expensive, no matter which method or combination of methods is chosen. The additional point should be made, however, that this early expense almost certainly will save money down the road, as the autistic child enters elementary school. Effective early intervention is likely to prevent the need for expensive separate programs, for example. Here, too, more research is needed, especially long-term research.

The following questions that were posed by conference participants are of special importance to parents and others serving on Interagency Coordinating Councils:

- **How do we establish operational models in our communities, not just theoretical models or models that exist only in other communities?**
- **How do states take all the information and integrate it into effective programming, without prescribing one model or approach for the whole state?**
- **How do states develop a set of individualized interventions without developing a "state system"?**
- **How can we establish methods for disseminating information to parents and professionals and for providing training and technical assistance?**

As a parent myself, of an adult daughter with autism, I recognize the dangers of parents becoming teachers. While we certainly want to instill in all our children certain standards of behavior, we must be cautious about constantly teaching, especially correcting, our children with autism. When we fall into that trap we undermine the healthy growth of self esteem in our children. While such a caution applies to all our children, it is especially important for our autistic children because it is so tempting to continually correct them: their language, their social behavior, their obsessions. One of the speakers made this point succinctly by urging that we see the "child" first, then the autism.

Currently, there is a rich supply of helpful literature on the subject of autism. Two recently published books are especially useful to parents and anyone working with children with autism:

Thinking in Pictures and other reports from my life with autism, by Temple Grandin. Published in 1995 by Doubleday, this book is widely available. In just 206 pages, Temple Grandin explains what it has been like to grow up autistic. She summarizes the latest findings about autism and vividly describes her own experience. In addition to her career in designing pens for livestock (she has a Ph. D. in animal science from the University of Illinois), Grandin has become a national expert in autism. She has talked with hundreds of parents and people with autism.

Out of Silence, by Russell Martin, was published by Henry Holt and Company in 1994. Martin writes about his nephew Ian, a boy with autism, growing up in Colorado. Always keeping his nephew as the central focus, Martin examines the latest chemical and neurological research on autism and the latest findings and theories about language development.

Many more excellent books and articles about autism are now available. NEC*TAS is in the process of compiling a bibliography on this topic. Temple Grandin lists several resources at the end of her book. Parents, educators, therapists, and administrators can benefit from Grandin's closing comments:

I would like to conclude...with a warning. There is no magic cure for autism, and parents must be cautious to avoid being misled by extravagant claims made by people who are promoting their brand of therapy. Treatments that are effective should work with reasonable amounts of effort. A treatment program that works for one child may be useless for another. Treatments and educational programs that are effective can be implemented without spending huge sums of money. Dedicated parents and good teachers have made their own effective programs after reading different books. They did not have to have expensive training. A parent should follow his or her own good instincts. Try different programs or methods and keep the things that work and eliminate the things that do not work. Combining several different approaches is often effective. (Grandin, page 222).

This Bulletin is prepared by the staff of the Federation for Children with Special Needs who participate in the National Early Childhood Technical Assistance System (NEC*TAS), which is funded through the U.S. Department of Education's Office for Special Education Programs (OSEP), Early Education Program for Children with Disabilities, under contract #HS-91-01-1001 awarded to the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill. Grantees undertaking such projects under government sponsorship are encouraged to express their judgment in professional and technical matters. Points of view or opinions, therefore, do not necessarily represent the Education Department's position or policy.

NECTAS

EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NECTAS

Winter 1999

ONE MOTHER'S REFLECTIONS:
Recent Reading About Autism

by Martha Ziegler, Coordinator, Massachusetts Autism Project
Federation for Children with Special Needs

We are now confronted with an explosion of interest and writing about autism. In one recent one-month period, over 200 people in the Greater Boston region attended each of three different meetings on autism; since all three meetings featured the same keynote speaker, Dr. Barry Prizant, there was probably very little duplication of attendees. Not long ago members of the local chapter of Autism Society of America, sponsor of one of the meetings, were pleased if 50 people came to a meeting.

This issue of ***Early Childhood Bulletin*** has been prepared to assist parents and their professional partners serving on Interagency Coordinating Councils with a useful resource to disseminate to other parents and service providers and to suggest directions for further reading.

Thirty-three years ago, when my daughter was evaluated at the Yale Child Study Center in New Haven, Connecticut, then director of the Center, Dr. Sally Provence, wisely recommended that my husband and I not bother reading any books on autism but instead begin to work with our daughter. I say this was a wise recommendation because she knew that the only book available was Bruno Bettelheim's ***The Empty Fortress***, in which he claimed that autism was caused by cold mothering.

Today's parents and professionals are fortunate to have so many skillful, knowledgeable writers available, among them parents, people with autism, and various professionals. For this article, I reviewed seven books and booklets, dating from one originally published in England in the 1960s to one appearing just a few months ago. Of the hundreds of books now available, I chose books that I believe are especially helpful and interesting for parents of young children with autism, for parents confronted with overwhelming and seemingly urgent decisions. Over the past two years I have read several other recent books, and many more during my daughter's lifetime. Among these additional books, not reviewed here, that I highly recommend are Temple Grandin's ***Thinking in Pictures***, Russell Martin's ***Out of Silence***, and Clara Claiborne Park's ***The Siege***.

While my selections have been personal, made as a parent and as a parent advocate, all the books mentioned here should be of interest to teachers and therapists as well as parents.

(Note: For the sake of brevity, this discussion uses the term "autism" to include "autism spectrum disorder," "pervasive developmental disorder (PDD)," and "pervasive developmental disorder not otherwise specified (PDDNOS).")

Four Emerging Themes

In reading and reflecting, I found several important themes emerging:

1. Respect for the people with autism themselves has increased greatly. No longer are they seen as having deliberately retreated to some secret, inner world. Nor are they any longer viewed as automatons who must be trained into compliance. They are, instead, seen as significant, individual people who live with a variety of neurological problems that make their lives difficult and complex.

2. Writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored.

"Respect for the people with autism themselves has increased greatly. No longer are they seen as having deliberately retreated to some secret, inner world."

3. Most of the writers whose books I have reviewed for this article agree that what often works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate. Several also advocate inclusion of such additional techniques as sensory integration, speech and language therapy, and facilitated communication for older children still not speaking. All agree that a structured environment is necessary, especially for young children with autism, no matter what types of intervention may be employed, and all emphasize the importance of integration with nondisabled peers as early as possible.

4. Parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly and indirectly.

Recommended Reading

I found that several of the most important books on autism have been regularly updated as new information has been acquired. For example, my copy of ***Children Apart: Children with Autism and Their Families*** by Lorna Wing, has been updated in 1985, 1991 and 1993. In 1974, with Dr. Wing's permission, the Autism Society of America (ASA) revised the book for use by readers in the United States. Wing, who is a parent and also a noted psychiatrist in England, originally published her book in the 1960s. In rereading it, I found that it still is the most important, basic introduction to the subject of autism. Wing and her later editors give a clear description of the syndrome, including the strange history of autism. They clearly and dispassionately present brief descriptions of the various kinds of intervention, concluding that children are served best when various methods are employed. This booklet should be given to every family with a newly diagnosed child with autism.

Right from the Start A helpful discussion of intensive behavioral intervention is contained in a new book (1998), ***Right from the Start: Behavioral Intervention for Young Children with Autism***, by Sandra L. Harris and Mary Jane Weiss. The authors are associated with the Douglass Developmental Disabilities Center at Rutgers University. They make a distinction between "early intensive behavioral intervention" and some of the more common terms like "applied behavior analysis" (ABA). Their terminology discussion is very helpful.

Although Harris and Weiss insist that "applied behavior analysis is essential in the treatment of every child with autism," they do cite several other "exemplary programs" utilizing various approaches: The preschool system in Montgomery County, Maryland public schools; Division TEACCH, University of North Carolina Medical School, Chapel Hill, originators of the teaching methodology now used in many places to teach children with autism; the Walden School, Emory University, Atlanta, Georgia, a toddler-preschool program utilizing a method called "incidental teaching"; and the Princeton Child Development Institute, Princeton, N.J.

In a section called "Common Features of Excellence," Harris and Weiss list the elements that appear again and again in very good early intervention programs: "a rich ratio of adults to children, opportunities for integration with nor-

mally developing peers, careful planning for the transition from the specialized program to a more normalized program, opportunities for family involvement, and a well developed curriculum" (p. 45). It is interesting to note that these qualities characterize all the effective program models for young children with autism, not just those utilizing an ABA approach.

Right from the Start is reader friendly and a little more open to other ideas than is often the case with writing on ABA and some other approaches that have enthusiastic supporters. The writers have achieved this style while still presenting a strong, clear case for their approach.

Movement Differences and Diversity in Autism/Mental Retardation by Anne M. Donnellan and Martha R. Leary, revised in 1997, is a helpful introduction to the theory of autism as essentially a movement disorder, a concept gaining wider acceptance. Donnellan and Leary, Philip Teitelbaum, Ralph Maurer, and others who write about movement disorder, are not talking about a motor problem, that is, difficulty walking or running; rather, they are describing a neurological barrier that makes it difficult for people with autism to initiate movement, especially production of language, to make transitions from one activity to another, and sometimes to stop or sustain an activity.

This, too, is a reader-friendly, accessible presentation of a complex idea, one that has enormous implications for the way parents and others view people with autism. It is a theory that views them as people with much more competence than earlier theories ascribed to people with autism. Furthermore, Donnellan and Leary have the refreshing habit of admitting earlier mistakes in their own thinking. Donnellan and Leary acknowledge the effectiveness of the discrete trial format as a teaching strategy, but they also urge some cautions, emphasizing the importance of considering the point of view and the needs of the individual child being taught. Because learning with this technique is such hard work, they insist that the behavioral goal be something important for the child, not something trivial or irrelevant, and they offer some useful hints in the application of this method.

Little Rain Man When I picked up ***Little Rain Man***, by Karen L. Simmons (1997), I assumed it was a book for children, but that is not the only, or even primary, audience. Written from the point of view of Simmons' young son Jonathan, it is a projection of what Simmons believes her son thinks and feels. It is an interesting example of one knowledgeable and creative mother's effort to help her son's siblings, teachers, and others understand him.

A Parent's Guide to Autism Charles A. Hart's ***A Parent's Guide to Autism***, published in 1993, continues to serve as one of the basic handbooks for parents, alongside Lorna Wing's ***Children Apart***. Hart has lived with autism both as a brother and then as a father. The 16 chapters of his book pose a series of 16 questions on the minds of almost every parent dealing with autism. Hart begins his chapter on education with the following crucial reminder: "Make sure the school sees your child as an individual, not just as a label or disability. If the word autism becomes the focus, instead of the person, the student and his or her potential could be lost behind the label" (p. 186).

"Writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored."

Hart has a talent for posing some of the most difficult questions and then answering them in a straightforward, commonsense manner. For example, in discussing the causes of autism he agrees with all other current observers that there is a neurological basis for the disability, but he carefully and clearly explains that it comes from a structural rather than a chemical problem in the brain. (Not all researchers agree with Hart on this point, however.) He further emphasizes the fact that there is no cure for autism, no miracles, no magic drugs, but effective education often achieves what looks like miraculous improvement and habilitation. In answering the question, "Why are there so many approaches to education?" he replies that this situation is a result of everchanging theories about the cause of autism. He further points out "Almost any serious

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attempt at education will help some of the students some of the time. For this reason, many of the earliest theories of education still have believers. However, careful evaluation at Division TEACCH and other research centers is making a difference. Education is becoming more of a science and less of a guessing game" (p. 193).

Recent Resource Guides from the States

Several states, including Massachusetts, have recently published their own excellent resource guides and handbooks on autism/PDD. One effective, readable document is the one published for Pennsylvania called, "What We are Learning About Autism/Pervasive Developmental Disorder: Evolving Dialogues and Approaches to Promoting Development and Adaptation." (1997) This is a well-written, well organized primer for helping parents and practitioners with decision making.

"Most of the writers whose books I have reviewed for this article agree that what often works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate."

The Pennsylvania booklet contains brief but clear summaries of the various components in the assessment of autism/PDD: Communication, sensory and movement regulation, learning differences, age and developmental sequence, possible concurrent psychiatric disorders and medical conditions, interests and capacities, friendships and relationships, and social context. Several descriptions are illustrated with real life stories from parents or teachers.

This handbook also contains a comprehensive chapter on the various methodologies and treatments now being offered. There is a brief discussion of such therapies as medication, auditory training, visual training, use of Irlen lenses (colored filters that have helped some children with autism with their visual processing), and biochemical readjustment through supplements and diet. The authors conclude this section with the following statement: "While some medical approaches may be intriguing to investigate, they are no substitute for the lifelong benefits of an appropriate education. Therefore, the following discussion will offer an outline of the *education, accommodation and support strategies* utilized by current teaching methodologies: Applied Behavior Analysis, Developmental or Relationship-based Approaches, Incidental/Naturalistic Teaching, Language and Communication Strategies, Movement Differences and Accommodations, Sensory Integration/Sensory Regulation, Social Skills Training, and Structured Teaching" (pp. 33-34). Each of these methodologies is discussed at some length.

The section on applied behavioral analysis (ABA) is especially helpful because it clarifies often misused terminology, including behavior modification, discrete trial training, and other behavioral techniques.

Several of the handbooks and resource guides published by state agencies have been the outgrowth of state level autism task forces or committees that emerged from the two conferences on autism sponsored by the National Early Childhood Technical Assistance Sytem (NECTAS) held in 1997. Similarly, NECTAS is following up with the preparation of a Policy Options and Considerations paper and a monograph on effective practices that are now being developed with the input of key stakeholders throughout the country. This publication will be widely disseminated to early intervention and preschool practitioners and parents.

Targeting Autism Finally, for a truly comprehensive review of current thinking about autism, I strongly recommend Shirley Cohen's ***Targeting Autism***, just published by the University of California Press. Professor of Special Education at Hunter College of the City University of New York, Cohen has been involved in the education of children with autism intermittently for 30 years. In this book, she reviews the latest research findings around possible causes of the disorder (Bristol, Denckla, Bauman, Teitelbaum, and others) and she reviews the history and current status of the leading teaching approaches: Lovaas, TEACCH, Greenspan's developmental approach, the Picture Exchange Communication System (PECS), the Koegel approach, and others.

Cohen has an interesting, respectful chapter on

what she terms "alternative treatments": megavitamin and other chemical therapies; auditory integration training; sensory integration therapy; and facilitated communication. She reports the fascinating observation made by Martha Denckla, research neurologist at Johns Hopkins University, that "alternative treatments like auditory integration and sensory integration are closer to the cause of autism than are behavioral approaches" (p. 142). That observation, however, in no way implies that any therapy is more important than good education.

Throughout the book Cohen relies on reports from several adults with autism who have the ability to report on their personal experience. She raises and examines several controversial issues, including those around the newer labels and around the concept of "recovery." She deals at some length with the question of equity; she is disturbed by the fact that generally speaking, only wealthy parents are having access to the intensive, lengthy intervention that is needed when the children are first diagnosed.

I was struck by Cohen's observations in the following paragraph, which confirm what I was seeing as I reviewed the other books:

"A funny thing seems to be happening out there in the world of educational/therapeutic treatment of autistic children. Common elements are appearing in approaches that were considered very different, even antagonistic, as programs learn and borrow from each other. People seem more willing to acknowledge that maybe they haven't had all the right answers. The director of a school that describes its goal as recovery and its approach as applied behavioral analysis told me: 'Maybe it's time to think of a TEACCH model for some children who show few signs of movement toward recovery after a year or two.' The more gentle and loving hand long espoused by programs based on a developmental approach seems to be creeping into programs derived from the Lovaas framework; and the principal theorist of developmental intervention, Stanley Greenspan, is talking about combining behavioral and developmental approaches to better fit the needs of some children" (p. 117).

This is an exciting, although challenging time to be working with young children with autism. We seem to be on the threshold of major scientific discoveries that surely will lead to prevention, or possibly even cure, of the disorder in all its varied manifestations. At the same time, now, parents, state coordinators of early intervention and preschool programs, and state interagency coordinating councils face the immense challenge of finding ways to provide and fund the intensive programs that are needed for the two years or so following diagnosis of the autism spectrum disorder.

"Parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly and indirectly."

Personally, as a parent and advocate I believe that the U.S. Department of Education's early intervention and preschool programs, including demonstration and outreach projects, along with National Institutes of Health research initiatives, have helped push forward earlier diagnosis and development of more effective treatment and teaching methods for our young children with autism. NECTAS, with its core of knowledgeable parents and leading educators and researchers, plays a crucial role as catalyst for this progress.

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Resources

To order materials and request additional information, contact:

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Legal Issues Under IDEA

"The 'Dos and Don'ts' of Avoiding Litigation: School Districts & Services for Young Children with Autism" 77
(Mandlawitz, 1998)

"Young Children with Autism: Navigating the Legal System" 81
(Mandlawitz, 1998)

"Mediation in the Individuals with Disabilities Education Act" 111
(Feinberg & Beyer) (*ADR Report*, 1998, 5-8)

The "Dos and Don'ts" of Avoiding Litigation:
School Districts & Services for Young Children with Autism

Myrna R. Mandlawitz, Esq.
August 1998

Many school districts across the country have found themselves embroiled in due process hearings and court cases on provision of appropriate programming for young children with autism. In my review of these cases, it is clear that these cases are often lost on procedural, rather than substantive, issues, i.e., school districts lose when they fail to "cross the 't's and dot the 'i's."

The following list of "dos and don'ts" should provide school districts some guidance in addressing issues related to serving young children with autism. This will all sound very familiar now, but don't forget it later!

Note: Cases cited are in the accompanying case list[1]. All of the cases in the case list will provide important insight into this area of the law, so don't stop at the ones cited below!

1. **Know the Law**

   School officials must be cognizant of federal and state laws regarding educating children with disabilities. Attorneys may cite not only the Individuals with Disabilities Education Act (IDEA), but also the Americans with Disabilities Act and the Rehabilitation Act of 1973.

   School officials should also know their state laws. State law may not offer less protection than federal law; however, state law may contain higher standards or greater protection. [See In Re: G (#72 in the case list), where the hearing officer looked to the higher state standard of "a full and fair opportunity to reach ... full potential."]

2. **Ensure that the IEP is developed in a timely fashion after the determination of eligibility.**

   Time lines must be followed. If the school district foresees that all evaluations will not be completed by the deadline or that there may be other extenuating circumstances, an extension of the time line should be sought.

   [See Delaware County Intermediate Unit (#3), where the school district determined the child's eligibility in September, but did not produce an IEP until January. The hearing officer stated that this was an egregious procedural violation.]

3. **(a) Give credence and respect to independent evaluators, i.e., evaluations sought by parents. (b) Heed the recommendations of your own — the school district's — evaluators. (c) Be sure that evaluators are qualified to adequately assess the child's needs, and, if possible, have an autism "expert" or consultant as part of the evaluation team.**

   (a) The IDEA requires that the IEP team review all available information, including independent educational evaluations brought by the parents. See Waterdown (#29), in which the school district representative at the IEP meeting stated: "The [school district] avers that Dr. Levine's [private evaluator] evaluation should be considered a non-observation. It merely shows her bias for a particular behavioral approach. Robin Goldberg's [private evaluator] evaluation should be given no weight as it is nothing more than a purchased opinion."

   (b) If the school district evaluations point in one direction, the IEP team should give serious weight to those evaluations. See Livermore Valley (#11) and Union School Dist. v. Smith (#4), in which district evaluators concurred with the program which the parents sought, while the district insisted on a program different from the one recommended by its evaluators.

   (c) Sometimes state regulations require specific personnel to participate in the evaluation. See Allegheny (#15), where state regulations require that an evaluation resulting in a determination of autism include

1 See pages 81-109: *Young Children with Autism: Navigating the Legal System* by Myrna K. Mandlawitz, Esq.

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assessments and diagnoses by a physician and a school psychologist.

On the topic of autism "experts," parents often will have had independent evaluations by such experts and will present them as expert witnesses, if necessary. The school district should be similarly prepared.

4. **Adjust the IEP, as appropriate, after reviewing results of independent evaluations or other relevant information or if the diagnosis changes after new assessments.**

   Be sure that all required IEP team members are present before any decisions are made. As stated earlier, the IDEA requires that full weight be given to all relevant information, including independent evaluations. Therefore, it the results of such an evaluation suggest a programmatic change, the team should comply. See Metuchen (#2), where the review panel noted positively that the school district had reassessed and modified the IEP after receiving reports from "highly skilled and credible" independent evaluators.

5. **All available evaluative information, school records, and other relevant information should be shared by parents and school district.**

   Both parties must be forthcoming with all available information in order to properly design a program and place the child in an appropriate setting. See Metuchen (#2), where the parents were penalized for withholding reports of an independent evaluation, thus making it impossible for the school district to complete the IEP within the designated time line.

6. **Do your homework, i.e., review all relevant information before making decisions.**

   See Waterdown (#29), where the IEP team had not reviewed the medical records or reports from early intervention providers prior to making program and placement decisions.

7. **(a) Develop goals and objectives before making placement decisions. (b) Be sure that those goals and objectives address all elements of the child's program, i.e., all of the child's needs.**

   (a) See Calaveras Unified School District (#5), where the IEP was found not be "legally sufficient," because goals and objectives were not developed prior to determination of placement. The hearing officer stated that this was "contrary to special education law and the spirit of the IDEA."

   (b) Programming must be predicated on the specific child's individual needs. Children should not be placed in a program because that is the program that the school district offers. It is appropriate to have a core program for young children with autism which includes different components; however, those components must be adjusted and manipulated to meet the child's unique needs.

   See West Bloomfield (#54), where the parents would not sign the IEP, contending that the program did not meet their child's needs. The school district representative stated that the number of hours proposed was "what is ordinarily provided in the county in our program for two and a half or 3-4 year old preschool youngsters."

   School districts should also seriously consider the need for extended year services, as regression is a often a major concern with children with autism.

8. **Offer parents a range of placement options.**

   Never present a program without explaining the range of available options. See Calaveras (#5), where the hearing officer found no evidence that any placement other than the one proposed was discussed: "Parents entering the educational system for the first time cannot be expected to be aware of the range of opportunities available to them. Without discussion or consideration of a continuum of placements, it is impossible for parents to meaningfully participate in the development of the IEP."

9. **If the district does not currently have an "applied behavioral analysis" program component available to young children with autism, consider implementing this component as an element of the larger program.**

10. **Teachers and other staff, including paraprofessionals, should receive inservice training in the newest methods in teaching young children with autism.**

    Evenfor the staff who are not "specialists" in autism, it is important that districts provide opportunities for continuing staff development. [See Metuchen (#2), where the

review panel noted positively that the teachers had participated in specialized, ongoing training.]

11. **Ensure that all procedural safeguards are met.**

School district officials should be conversant with proper notice requirements, with the requirement to inform parents of their rights under the law, and with the requirement that parents have a "meaningful opportunity to participate" in all program and placement decisions.

Young Children with Autism:
Navigating the Legal System

Myrna R. Mandlawitz, Esq.
Special Asst. for Government Relations
NASDSE [1]

A. THE "ISSUE":

1. **A "CASE STUDY":** Mr. and Mrs. Smith are the parents of 3-year-old "John" who has been diagnosed as autistic. John will not allow his parents to hold him, shows no change in expression when they approach, and does not make eye contact. For no apparent reason, John will begin to rock and bang his head against the wall, and the Smiths are at a loss as to how to comfort their son. John is unable to communicate even his most basic needs.

John's older brother, who loves toy soldiers, has tried repeatedly to get John to take one "side" in his pretend battles. John, however, spends his time lining the soldiers up in the exact order over and over again, with no attention to his older brother's game.

Worst of all, the Smiths are embarrassed to take John into a restaurant or to the local mall because his behavior is so unpredictable. The slightest unusual noise can set John off, and they can no longer stand the tantrums, screams, and self-destructive behavior. While they dearly love their son, for the whole family's sake, they believe that intensive help will be necessary for John to remain in the home.

1 National Association of State Directors of Special Education (NASDSE)
1800 Diagonal Road, Suite 320
King Street Station 1
Alexandria, VA 22314
Phone: (703) 519-3800 * TDD: (703) 519-7008
Fax: (703) 519-3808 * URL: http://www.nasdse.org/

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2. **THE "QUESTIONS":** The incidence of autism is now the same as that of Down Syndrome: 1.5 per 1,000. For families in crisis like the Smiths, behavior modification methodologies such as **"Lovaas"** and **"TEACCH"** often seem to be panaceas. However, the latest literature on autism presents mounting evidence that an eclectic approach to educating children with autism - rather than reliance on a single methodology - may produce the best results. How, then, do public schools, who are now seeing thousands of "Johns," accommodate parents' requests for intensive therapies such as Lovaas and TEACCH?

This question leads to others: Did Congress in fashioning P.L. 94-142 adequately anticipate the serious and intensive needs of this population? Under the IDEA, what is the definition of FAPE for preschoolers with autism? Can parents demand that the school district adopt a particular methodology? Can cost ever be a factor in determining level of service? Will school districts be held responsible for reimbursement for unilateral placements in private schools by parents who maintain that the district has not offered an appropriate placement?

To address these questions, a few definitions may prove helpful....

B. **DEFINITIONS:**

1. **AUTISM:** Autism is a pervasive developmental disability that typically appears by age three. The disability is a result of a neurological disorder that occurs in about 15 out of every 10,000 children born, and boys are three to four times more likely to be affected.

There is no known cause for autism, and common medical tests such as brain scans cannot reliably detect the disability. Autism may occur alone or in association with other disorders affecting brain function, e.g., viral infections and epilepsy.

A child may be labeled as autistic after observation of certain behavioral deficits in the areas of communication, symbolic and imaginative activity, social interaction, and certain stereotypical behavior patterns. Some of the behavioral symptoms identified with autism include --

(a) delays in physical, social, and language skills;

(b) abnormal sensory responses;

(c) absence of or delays in speech and language, although thinking capabilities may be present; and,

(d) abnormal ways of relating to people, objects, and events.

Children with severe autism may also exhibit self-injurious behavior and behaviors that are highly repetitive and aggressive.

2. **APPLIED BEHAVIORAL ANALYSIS (ABA):** Proponents of this treatment model subscribe to the view that the behavioral deficits exhibited by autistic children may be changed by an intensive focus on changing the individual behavior problems. Children with autism face two learning challenges in a behavior modification system -- reducing "behavioral excesses," e.g., tantrums and aggressive behavior; and, improving "behavioral deficits," i.e., appropriate spoken communication. To meet these challenges, skills which the child needs to master are broken down into small components, each of which is taught using behavioral cues, drills, and a system of

rewards. Some therapists also use aversives to change inappropriate behaviors; however, this practice has drawn heavy criticism.

The most extreme forms of this type of treatment require a highly structured environment and often are delivered through one-on-one therapy. The treatment is thought to be most effective when children receive ongoing "training" through their entire day, including parental "instruction" in the home. Behaviors learned in the classroom and in the home are reinforced in other settings, so that the behaviors become generalized.

Two examples of behavior modification programs are the Lovaas method and TEACCH (Treatment and Education of Autistic and Communication handicapped Children). Following is a brief description of these two systems:

a. **The Lovaas Method:** Named for Ivar Lovaas, a UCLA researcher who developed the method, "Lovaas" is a 30-40 hour per week therapy instituted preferably before age three. The therapy program begins with two years of one-to-one training from 4 to 6 hours a day, 5-7 days a week. Parents are trained to be "teachers," as well, so that therapy continues through the entire day and year.

   The method is based on operant conditioning. In other words, the child is presented with a discrete task using a particular stimulus. The child is then conditioned to respond in a particular manner and is presented with a reinforcing reward if the appropriate response is given. Small discrete tasks or behaviors are then used to build more complex behavior systems.

The therapy is presented by a "treatment team." Students from the Clinic for Behavioral Treatment of Children at UCLA have been involved in staffing these teams around the country. These students are supervised by more experienced therapists. In situations where UCLA students are not members of the team, the UCLA clinic will provide training to families through consultants trained in the Lovaas method. Therapy is often provided at home, and providers may not necessarily be certified special educators.

b. **TEACCH:** This method was developed by Dr. Eric Schopler of the University of North Carolina at Chapel Hill. Dr. Schopler is a strong critic of the Lovaas method and believes that the "recovery" rate under that system has been overstated. TEACCH, while containing a behavior modification component, is characterized by Dr. Schopler as a more "cognitive" approach to teaching self-care skills and managing disruptive behavior. The emphasis in TEACCH is on making use of skills that children already possess.

Also in contrast to Lovaas, TEACCH is presented by special education staff within the classroom who have received specific training in the methodology. Children perform tasks at special work stations, often separated by dividers from the rest of the class. The tasks are often repetitive, visual-motor activities. Children operate independently using certain cues.

C. **THE "LEGAL SYSTEM" ON METHODOLOGIES FOR YOUNG CHILDREN WITH AUTISM: WHERE DO SCHOOL DISTRICTS and PARENTS GO FROM HERE?** To begin to address the questions posed earlier and to see the trends that are

developing, it is necessary to examine what hearing officers and the "legal beagles" are saying. Following is a list of the decisions handed down by courts and hearing officers to date:

1. ***G.F. v. East Hanover Bd. of Educ.,*** 16 EHLR 141 (SEA NJ 1989). District's proposed program conferred "some educational benefit," and therefore was sufficient to meet its obligations under the law. No ruling was made on the issue of reimbursement.

2. ***Metuchen Bd. of Educ.,*** 1 ECLPR ¶ 294 (SEA NJ 1992). Administrative law judge found that district's proposed placement of 3-year-old in its intervention preschool program was appropriate. Further, parents failed to demonstrate that district's program was unable of meeting child's needs, and their request for out-of-district placement was unnecessary.

3. ***Delaware County Interm. Unit #25 v. Martin and Melinda K.,*** 831 F.Supp. 1206 (E.D. Pa. 1993), 20 IDELR 363. Court ruled that TEACCH-based program was inadequate to meet child's needs and that Lovaas method was appropriate. Parents awarded reimbursement for providing Lovaas therapy in their home.

4. ***Union Sch. Dist. v. Smith,*** 20 IDELR 987 (9th Cir. 1994). Circuit court upheld lower court ruling that district failed to provide FAPE to autistic child. Parents were granted reimbursement for costs of unilateral placement in Lovaas clinic, plus costs for transportation and lodging since clinic was beyond commuting distance. Court added further that if school district had offered appropriate program which was available at another school within the district, parents would not have received reimbursement.

5. ***Calaveras Unified Sch. Dist.,*** 21 IDELR 211, 2 ECLPR ¶ 23 (SEA CA 1994). Hearing officer determined that child was denied FAPE based on procedural violations in development of the IEP. Further, parents were not given meaningful opportunity to participate development of the IEP. Parents were awarded reimbursement for costs of Lovaas program and transportation to and from speech therapy. However, hearing officer also determined that proposed revised program was appropriate.

6. ***Central Susquehanna Interm. Unit 16,*** 2 ECLPR ¶ 109 (SEA PA 1994). Appeals panel ruled that, in order to benefit from his education, child did not require additional Lovaas program beyond the 15 hours per week offered by the intermediate unit

7. ***M.A. v. Voorhees Bd. of Educ.,*** Agcy Dkt. No. 94-5887 (NJ Office of Admin. Law 1994). Hearing officer ordered continuation of in-home program and immediate evaluation by school district. School district also ordered to hire consultant with expertise in Lovaas.

8. ***Mill Valley Elem. Sch. Dist.,*** 21 IDELR 612 (SEA CA 1994). Parents' request for 228-day per year educational program was denied; however, school district was ordered to provide maintenance program whenever there was a school break of two weeks or more.

9. ***Tuscaloosa County Bd of Educ.,*** 21 IDELR 826 (SEA AL 1994). Hearing officer upheld board's decision to discontinue services of private clinic using Lovaas method and instead use its own staff trained in the TEACCH method. Parents were denied reimbursement for unilateral placement in private school.

10. ***Sioux Falls Sch. Dist. v. Koupal,*** 526 N.W.2d 248, 22 IDELR 26 (1994). State supreme court ruled that teacher training for particular methodology -- in this case TEACCH -- could not be required in an IEP.

11. ***Livermore Valley Joint Unified Sch. Dist.,*** 2 ECLPR ¶ 65 (SEA CA 1994). Hearing officer found that district's program was insufficient to meet child's needs. Ordered reimbursement for tuition, transportation, and costs of supplemental in-home program.

12. ***Fairfax County Pub. Schs,*** 22 IDELR 80 (SEA VA 1995). State review panel found that district's proposed program was reasonably calculated to enable child to receive educational benefit. Parents' request for reimbursement for unilateral placement in private school using Lovaas method was denied.

13. ***Sherman v. Pitt County Bd of Educ.,*** 2 ECLPR ¶ 247 (SEA NC 1994), Final Decision, Jan 18, 1995 (not reported; decision available from author). Reviewing officer found that school board did not provide appropriate educational program. Parents were awarded reimbursement for reasonable costs incurred in educating child until child became eligible for public kindergarten or school district complied with requirement to provide free appropriate preschool education.

14. ***Frederick County Pub. Schs,*** 2 ECLPR ¶ 145 (SEA MD 1995). Hearing officer found that district failed to provide appropriate program and that child had received significant educational benefit while enrolled in private school using Lovaas method. Hearing officer also found that district failed to offer extended year services. Parents were awarded reimbursement for costs of Lovaas program in home, private preschool, and

summer therapies. Hearing officer also held, however, that parents had no right to require district to implement methodology of their choice.

15. ***Allegheny (PA) Intermediate Unit #3,*** 2 ECLPR ¶ 10 (SEA PA 1995). Parents requested full-day placement for 3-year-old, whereas IU proposed either partial day placement in mixed disability class or placement in LEAP program. Appeals panel agreed with hearing officer that LEAP program was appropriate. Therefore, parents were not reimbursed for discrete trial program. Reimbursement was granted for independent evaluation, which was significant in determining appropriate programming for the child.

16. ***Conejo Valley Unified Sch. Dist.,*** 23 IDELR 1081 (SEA CA 1995). Parents contended that instructional aide was not properly trained in Lovaas and behavior management techniques. Hearing officer concluded that training was sufficient.

17. ***Rebecca S. v. Clarke County Sch. Dist.,*** 22 IDELR 884 (M.D. Ga. 1995). District court found that student received "educational benefit" from TEACCH program and that residential placement was not necessary for child to continue to show educational progress.

18. ***Chester County Interm. Unit,*** 23 IDELR 723 (SEA PA 1995). Appeals panel found that IU provided appropriate placement for child in year-round, half-day early intervention program, allowing student to progress educationally in the least restrictive setting. Parents were denied reimbursement for in-home program using Lovaas method.

19. ***Foxborough Pub. Schs.,*** 2 ECLPR ¶ 126 (SEA MA 1995). Hearing officer found that district's IEP failed to provide program that would maximize student's educational

development in least restrictive setting. Ordered placement in private preschool program which hearing officer felt best met child's needs.

20. ***Capistrano Unified Sch. Dist.,*** 23 IDELR 1209, 2 ECLPR ¶ 187 (SEA CA 1995). Hearing officer ruled that child was receiving educational benefits from in-home therapy. District was ordered to reimburse parents for costs of in-home therapy and to provide 25 hours of one-to-one in-home therapy per week through the school year.

21. ***Peninsula Sch. Dist.,*** 27 IDELR 381 (SEA WA 1995). ALJ found several procedural violations by the district regarding evaluation of 5-year-old twins with autism., as well as finding that program was inappropriate based on inadequate evaluation. District was ordered to reimburse parents for costs of independent evaluation and costs of in-home program.

22. ***J.S. v. High Bridge Bd. of Educ.,*** 24 IDELR 589 (SEA NJ 1995). Parents did not contest content of program, but rather intensity. Hearing officer ordered 70 hours per week year-round of Lovaas program, with all costs paid by school district.

23. ***In re Child with Disabilities,*** 23 IDELR 471 (SEA CT 1995). Hearing officer found that school board's program was inappropriate and that home-based Lovaas program provided by parents was appropriate. Parents were awarded reimbursement for reasonable costs of in-home program until school board made FAPE available in less restrictive environment.

24. ***Kalamazoo City Pub. Sch. and Kalamazoo Valley ISD,*** 2 ECLPR ¶ 180 (SEA MI 1996). Hearing officer found that school district's IEP was appropriate and denied

reimbursement to parent for cost of summer program and tutoring costs when child was withdrawn from school. Affirmed on appeal.

25. ***Board of Educ. of the City Sch. Dist. of the City of NY,*** 24 IDELR 199 (SEA NY 1996). Hearing officer found public school placement appropriate; parent appealed. Parent failed to establish that private school offered an instructional program to meet child's needs. Appeal dismissed.

26. ***Kalamazoo Valley ISD and Sch. Dist. of the City of Kalamazoo,*** 2 ECLPR ¶ 209 (SEA MI 1996). District refused to adopt parents' proposed IEP for year-round, in-home Lovaas program. During dispute, parents arranged in-home program and sought reimbursement. Hearing officer concluded that district program was appropriate and denied reimbursement. NOTE: See appeal, #26.

27. ***Board of Educ. of the Greenwood Lake Union Free Sch. Dist.,*** 23 IDELR 1032 (SEA NY 1996). School offered TEACCH program; however, parents wanted continuation of in-home Lovaas program. Reviewing officer concluded that TEACCH program was appropriate and met least restrictive environment requirement. Parents were not entitled to relief.

28. ***San Bruno Park Elem. Sch. Dist.,***2 ECLPR ¶ 201 (SEA CA 1996). Parents unilaterally enrolled child in home program after refusing assessment by district. District argued that home program was substantial change in placement and therefore warranted reassessment. Hearing officer held that district was entitled to conduct assessment and could use its own assessor, as the law does not require the district to select a professional who supports the methodology proposed by the parents.

29. ***Watertown Pub. Schs.***, 24 IDELR 92, 2 ECLPR ¶ 196 (SEA MA 1996). Parents requested full-day, full-year program with behavioral component and home component. Four-year-old had been attending integrated preschool program with home component, the latter based on different behavioral approach. Hearing officer concurred with parents' request, and district was ordered to design appropriate program based on this model.

30. ***Columbia Regional Programs and Portland Sch. Dist.***, 24 IDELR 98 (SEA OR 1996). Parents sought continuation of in-home Lovaas program, reimbursement for costs of program, and extended year services. Hearing officer determined that initial IFSP was appropriate; however, the early childhood special education program later proposed was not. District ordered to reimburse parents for various costs related to home program and for independent evaluation. NOTE: See #28 below.

31. ***School Dist. of the city of Kalamazoo***, 2 ECLPR ¶ 232 (SEA MI 1996). District offered placement in pre-primary impaired classroom with discrete trial methodology, in-home services, and related services. Parents sought longer hours exclusively in-home program. Review officer affirmed hearing officer's ruling that district program was appropriate.

32. ***Malkentzos ex rel. MM v. DeBuono***, 923 F.Supp. 505 (S.D.N.Y. 1996), 24 IDELR 211. District court found that state was unable to show appropriateness of its early intervention program, and the unavailability of trained personnel did not excuse statutory obligation. Court granted parents' request for injunctive relief and compensation for expenses incurred. NOTE: See Second Circuit decision, #46.

33. ***Multnomah Educ. Serv. Dist.; Columbia Reg. Prog.; Portland Sch. Dist.; Oregon Dept. of Educ.,*** 24 IDELR 606 (SEA OR 1996). Hearing officer amended previous order, adding Multnomah and OR Dept. of Education as parties and clarifying that student was to continue in-home Lovaas program through the end of the school year.

34. ***Cobb County Sch. Sys.,*** 24 IDELR 875 (SEA GA 1996). District did not comply with time lines for development of the IEP, nor did it consider the child's individual needs after child was diagnosed with autism. Hearing officer determined that district's proposed program was not adequate to meet the student's needs, citing both procedural and substantive violations. District was ordered to reimburse parents for cost of one year of Lovaas program.

35. ***In Re Still v. DeBuono,*** 927 F.Supp. 125 (S.D.N.Y. 1996), 24 IDELR 334. Parent of infant sought reimbursement for costs of teachers under Lovaas-type program, claiming that Part H lead agency had denied child an appropriate education. District court consolidated this action with *Malkentzos* and incorporated holding from that case in its entirety. NOTE: See Second Circuit decision, #46.

36. ***Allamakee Community Sch. Dist. and Keystone AEA 1,*** 24 IDELR 516 (SEA IA 1996). Parent argued that district's extended year program denied FAPE, citing insufficient number of instructional hours. ALJ, after finding numerous procedural and substantive violations, concluded that district offered sufficient number of hours of appropriate instruction, but didn't offer "structured play" component. District ordered to modify IEP to include current level of performance and social interaction component.

37. ***Board of Educ. of the Ann Arbor Pub. Sch.,*** 2 ECLPR ¶ 236, 24 IDELR 621 (SEA MI 1996). Parents requested 40 hours per week of discrete trial training, extended year

program, and home component. Hearing officer found numerous procedural violations and determined that parents' program requests were appropriate. Subsequently, State review officer overturned local hearing officer's decision. Specifically, he concluded that local hearing officer erred in ruling that the parties' proposals were not competing methodologies. (***In the Matter of Martin Renner v. Ann Arbor Pub. Schs.***, unpublished decision, Case No. H-0293-96, Sept. 14, 1996)

38. ***Parchment Pub. Schs./Kalamazoo Valley Interm. Sch. Dist.***, 2 ECLPR ¶ 259 (SEA MI 1996). IEP team did not consider student's needs, current program, or progress in that program; therefore, IEP was not based on unique needs of the child. Procedural violations in development of the IEP constituted denial of FAPE. Parents' Lovaas program was "appropriate," entitling them to reimbursement for half the costs related to in-home program.

39. ***Baltimore County Pub. Sch.***, 2 ECLPR ¶ 231 (SEA MD 1996). Parents claimed district's services were insufficient and instituted in-home Lovaas program. District's program was upheld at local level, but review panel concluded that district program did not confer "educational benefit." Parents awarded reimbursement for in-home program.

40. ***Inland Regional Center/San Bernardino Cty Superint. of Sch.***, 2 ECLPR ¶ 244 (SEA CA 1996). ALJ ruled that intensive early intervention program was appropriate and that parents should be reimbursed for some expenses. Clarification was issued on ALJ's ruling since parents would be using new service provider not yet vendored by lead agency.

41. ***Board of Educ. of the Syosset Cent. Sch. Dist.***, 2 ECLPR ¶ 257 (SEA NY 1996). District provided an appropriate placement, and there was no evidence that additional Lovaas

services requested by parents were needed to meet the IEP goals. Parents' requests for ABA therapy as supplement to school program and for reimbursement for in-home program were denied.

42. ***Board of Educ. of the City Sch. Dist. of the City of N.Y.***, 2 ECLPR ¶ 241 (SEA NY 1996). District proposed placement in school for autistic and PDD children, where child would receive ABA program. Parents requested continuation of in-home ABA program, with payment by district. Hearing officer concurred with district proposal. Review officer affirmed, finding that center-based program was least restrictive environment.

43. ***Long Beach Unified Sch. Dist.***, 2 ECLPR ¶ 271 (SEA CA 1996). District's refusal to fund in-home program was denial of FAPE, since district program was not designed to meet child's individual needs. Although progress was evident while child was in district program, in-home program was determined to be partially responsible for that progress. District ordered to reimburse parents for cost of in-home program and to provide a similar program for the coming school year, with program component in district preschool.

44. ***Independent Sch. Dist. No. 318***, 24 IDELR 1096, 2 ECLPR ¶ 268 (SEA MN 1996). District had a "fundamental misunderstanding" of student's disability and unique needs. District program did not provide any educational benefit, whereas in-home Lovaas program did. Parents awarded reimbursement for in-home program. ALJ also ruled that aide must be trained in Lovaas therapy and that autism professionals be included on IEP team.

45. ***Cobb County Schs.***, 24 IDELR 1113 (SEA GA 1996). District program was determined to be appropriate and designed to provide educational benefit in the least restrictive environment. ALJ concluded that there were no procedural violations regarding

delays in meeting time lines. Therefore, request for reimbursement for in-home Lovaas program was denied.

46. ***Berks County Interm. Unit No. 14***, 2 ECLPR ¶ 276 (SEA PA 1996). Parents' procedural rights were not violated with regard to participation in the IEP process. Intermediate unit's IEP was appropriate and designed to provide "meaningful" educational benefit, as evidenced from student's progress and incorporation of recommendations of outside evaluator. Parents' request for reimbursement for in-home Lovaas program was denied.

47. ***Student v. Somerset County Board of Educ.***, 2 ECLPR ¶ 251 (D.Md. 1996). Although not an "ABA" case, this is an interesting twist on the education of children with autism. Parents requested placement in regular education class with supplementary aids and services for 10-year old with autism. Court found that district's proposed placement in segregated setting was appropriate and in compliance with least restrictive environment requirement, given student's need for highly structured environment and safety concerns. Court concluded that amount of mainstreaming offered was sufficient. Other claims under ADA, Section 504, and Section 1983 were dismissed.

48. ***Houston Indep. Sch. Dist.***, 2 ECLPR ¶ 278 (SEA TX 1996). Although district did not complete assessment within time line, student was not denied FAPE since procedural violation did not result in any harm and was not unreasonable under the circumstances. IEPs were appropriate and proposed placements met least restrictive environment requirement. Parents' request for reimbursement for in-home ABA program was denied.

49. ***Board of Educ. of the City Sch. Dist. of the City of Troy,*** 2 ECLPR ¶ 280 (SEA NY 1996). District had offered 30 hours per week of ABA therapy; however, parents requested 40. Hearing officer remanded case back to committee on preschool special education (CPSE). Parents appealed, challenging authority of hearing officer. Review officer concluded that hearing officer had been improperly selected and remanded case back to CPSE to recommend IEP and placement for next school year.

50. ***Board of Educ. of the Lawrence Union Free Sch. Dist.,*** 2 ECLPR ¶ 281 (SEA NY 1996). Hearing officer concluded that district program, which incorporated 30 hours of ABA instruction in an intermediate unit, was appropriate. Parents had requested an additional 25 hours of home-based ABA. Review officer upheld hearing officer's decision.

51. ***San Diego City Unified Sch. Dist.,*** 3 ECLPR ¶ 7 (SEA CA 1996). Proposed IEP failed to address child's individual needs, including lack of behavioral plan. Hearing officer concluded that student needed intensive in-home one-on-one therapy, which was not included in IEP. District was ordered to fund student's current in-home program, plus program supervision, parent training, and occupational therapy. Since in-home program was deemed appropriate, parents were reimbursed for in-home program.

52. ***Lincoln Consol. Schs.,*** 2 ECLPR ¶ 275 (SEA MI 1996). District committed procedural violation when it held IEP meetings without inviting or including parents. Hearing officer concluded that parties had reached an oral agreement on proposed IEP. Therefore, when subsequent IEP failed to conform to terms of oral agreement, student was denied FAPE. District ordered to implement IEP as agreed upon and reimburse parents for in-home Lovaas program.

53. ***Malkentzos ex. rel. MM v. DeBuono,*** 25 IDELR 36, 3 ECLPR ¶ 2 (2d Cir. 1996). Court concluded that injunctive order for retrospective relief was improper and remanded claim to district court for decision as to whether parents were entitled to reimbursement for uncertified ABA therapy. Court vacated order for prospective injunctive relief due to mootness, since child had aged out of eligibility under Part H by the time of the hearing.

54. ***West Bloomfield Sch. Dist.,*** 3 ECLPR ¶ 17 (SEA MI 1996). Determination of whether Lovaas was appropriate methodology was determined to be within hearing officer's authority. Student denied FAPE due to procedural violations regarding evaluation and refusal to discuss Lovaas as possible program option. Parents entitled to reimbursement for in-home program, since that program was deemed appropriate.

55. ***Bayonne Bd. of Educ. v. R.S. by K.S. and S.S.,*** 25 IDELR 700 (D. N.J. Jan. 2, 1997). Parents unilaterally placed preschooler in private school, and requested that they be reimbursed for costs. Settlement agreement provided for district to pay for private school while transition plan was implemented. Another hearing was requested before plan was completed, with parents requesting continuation in private placement. Court determined that "stay put" was private school, and district was required to pay for costs of private program pending final outcome of hearing.

56. ***Walker County Sch. Sys.,*** 26 IDELR 440 (SEA GA 1997). Administrative law judge ruled that the proposed IEP failed to offer the 8-year-old student a FAPE. Student, previously in the district school, had made no progress; however, in private placement using the TEACCH method, the student progressed. District also committed additional procedural

violations, including failure to respond to a request for extended year services and failure to develop a behavior plan.

57. ***Los Alamitos Unified Sch. Dist.,*** 26 IDELR 766 (SEA CA 1997). 5-year-old was receiving home-based discrete trial training provided by district. District proposed to continue therapy in school setting. Parents objected. Hearing officer determined that move to school setting constituted a change in placement and ordered home-based program to be continued.

58. ***Board of Educ. of the City Sch. Dist. of the City of White Plains,*** 25 IDELR 872, 3 ECLPR ¶ 35 (SEA NY 1997). District proposed program which included 26 hours of ABA. Parents challenged number of hours and requested reimbursement for home-based program. Hearing officer ordered 40 hours of ABA. District appealed, and review officer concluded that student did not require 40 hours of therapy in order to make educational progress. Parents were denied reimbursement because district program was appropriate.

59. ***Flour Bluff Indep. Sch. Dist.,*** 25 IDELR 1121, 3 ECLPR ¶ 43 (SEA TX 1997). IEP and district program was held to be appropriate, but required some modification. District was determined to have denied FAPE during summer of 1996. Therefore, parents were entitled to reimbursement only for extended year services that would have been provided during that period.

60. ***Lexington County Sch. Dist. Five,*** 25 IDELR 933 (SEA SC 1997). Hearing officer rejected parents' contention that district committed procedural violation. Determined that district was ultimately responsible for student's education and that every effort had been

made to include parents in planning. Program was determined to be appropriate, and reimbursement was denied, including request for attorneys' fees.

61. ***Board of Educ. of the North Rose-Wolcott Central Sch. Dist.,*** 26 IDELR 325 (SEA NY 1997). District proposed out-of-district placement for 7-year-old. Parents requested home-based ABA program. Hearing officer ruled that district committed procedural violations and ordered in-home ABA. Review officer also found procedural violations and concluded IEP was invalid. District was ordered to continue in-home instruction, but choice of methodology was left to the district.

62. ***Portland Pub. Schs.,*** 26 IDELR 96, 3 ECLPR ¶ 68 (SEA ME 1997). Hearing officer determined that there were numerous procedural violations in development of several IEPs. Although hearing officer noted that methodology was usually within purview of district, not parents, numerous procedural violations entitled parents to methodology requested. District was ordered to provide ABA therapy and to ensure adequate trained personnel.

63. ***Shoreline Sch. Dist.,*** 26 IDELR 923, 3 ECLPR ¶ 86 (SEA WA 1997). Parents rejected proposed IEP, calling for placement in developmental classroom and requested in-home Lovaas program. ALJ concluded that proposed IEP was appropriate; therefore, parents were not entitled to reimbursement for in-home program.

64. ***Azle Indep. Sch. Dist.,*** 26 IDELR 931, 3 ECLPR ¶ 87 (SEA TX 1997). District offered program to 4-year-old in special education preschool classroom. Parents requested district funding of in-home Lovaas arranged by parents, in addition to preschool program. Hearing officer held that district committed procedural violations in not timely assessing

student for autism and not providing services specified in previous IEP. Although hearing officer found district's program deficient, also determined that parents failed to show necessity for in-home program. Ordered preschool program plus 10 hours of Lovaas.

65. ***Petersham Pub. Schs.,*** 26 IDELR 703 (SEA MA 1997). Issue revolved around parents' disagreement with change of schools. Hearing officer concurred with parents' expert that change would be detrimental to student. Hearing officer ordered continuation of current placement.

66. ***Mr. X v. New York State Educ. Dept.,*** 26 IDELR 854 (S.D.N.Y. Sept. 5, 1997). Committee on preschool education proposed a center-based program, including 25 hours a week of ABA instruction, for 3-year-old with autism. Parents rejected proposed IEP and requested continuation of 40-hour a week in-home ABA program. Hearing officer and review panel ruled for the district. District court reversed, stating that IEP was not designed to allow educational benefit and failed to make recommendations based on the child's diagnosis.

67. ***Old Adobe Union Elem. Sch. Dist.,*** 27 IDELR 70 (SEA CA 1997). Parents who provided in-home ABA program and preschool challenged several years' of proposed placements. Hearing officer concluded that proposed IEPs and placements were inappropriate because the objectives were too general and failed to address the student's individual needs. Hearing officer further noted that child progressed in home program, continuation of which was recommended by several professionals.

68. ***Taunton Pub. Schs.,*** 27 IDELR 108 (SEA MA 1997). Three-year old with autism participated in home ABA program, while school district recommended diagnostic

placement. Parents agreed with placement but also requested that district assume payment for in-home program. Hearing officer ruled that IEP was procedurally and substantively flawed and that diagnostic placement was inappropriate since diagnosis was not disputed. Order included continuation of in-home training and compensatory educational services.

69. ***Douglas ESD/Oregon Dept. of Educ.,*** 3 ECLPR ¶ 124 (SEA OR 1997). District's proposed IFSP for two-year-old with autism included in-home ABA therapy and speech therapy. Parents supplemented with additional ABA therapy and challenged IFSP. Hearing officer noted that under Part H, district are required to provide "services designed to enhance the development" of infants and toddlers with disabilities and that IFSP was appropriate.

70. ***Washoe County Sch. Dist.,*** 27 IDELR 134 (SEA NV 1997). School district proposed TEACCH program for four-year-old with autism. Parents rejected proposal and requested reimbursement for in-home Lovaas program. Hearing officer concluded that IEP was appropriate. Hearing officer also noted that methodology decisions are left to the school district; therefore, district not required to use Lovaas or reimburse the parents.

71. ***Henderson County Pub. Schs.,*** 27 IDELR 435 (SEA NC 1997). District prevailed when ALJ determined that district placement was appropriate. Parents were providing in-home Lovaas program for 7-year-old. District proposed placement in regular kindergarten for half day with one-on-one aide, hour a day in autism classroom, and additional one-on-one academic instruction. ALJ said that child seemed to have made little progress in Lovaas program, and program did not meet child's needs for development of functional language and independent living skills.

72. ***In Re: G,*** 27 IDELR 451 (Dept. of Defense, NC 1997). Parents substantially prevailed when school district proposed IEP with placement in self-contained classroom. Five-year-old was receiving Lovaas training at home. Hearing officer determined that child did not progress in DDESS program and actually regressed. District was required to continue Lovaas instruction in a classroom setting, after child completed third year of in-home program. Child was also to receive year-round services.

73. ***Washoe County Sch. Dist.,*** 27 IDELR 560 (SEA NV 1997). District prevailed when review officer agreed that proposed IEP was appropriate. Proposed IEP for 4-year-old was based on evaluations which complied with all requirements and was designed to meet the child's individual needs. Parents had requested in-home Lovaas program and reimbursement for previous costs.

74. ***Mr. and Mrs. "B" v. Board of Educ. of the Syosset Sch. Dist.,*** 27 IDELR 685 (E.D.N.Y. January 15, 1998). Parents of 5-year-old challenged district's refusal to include in-home ABA program in student's IEP. Hearing officer held that district was not required to include ABA. On appeal, state review officer affirmed hearing officer's decision. Parents filed complaint in federal district court, alleging violations of IDEA, Rehabilitation Act, Section 1983, and state statutes. Court dismissed claims, finding that parents failed to allege that school system had denied FAPE, i.e., that evidence was not sufficient to state an IDEA claim.

75. ***Board of Educ. of the City Sch. Dist. of the City of New York,*** 3 ECLPR 174 (SEA NY 1998). Parents challenged proposed IEP and placement, requesting rather that district fund placement in private center. Hearing officer found for the district. Review

officer reversed, stating that district's proposed placement was not designed to meet student's individual needs and would not allow for sufficient progress. However, review officer denied parents' request that district place child in private center, stating that not enough evidence was presented to determine that the private placement was appropriate.

76. ***Ontario-Montclair Sch. Dist.,*** 28 IDELR 232 (SEA CA 1998). Parents rejected proposed placement, the same class child had attended previously. Parents began in-home program. Hearing officer found that district did not offer parents any choices and that placement was inappropriate, with no measurable progress discernible. Hearing officer found that child made rapid progress in in-home program, i.e., program provided a FAPE, District was ordered to reimburse parents and to pay for program through school year. In addition, district was ordered to transition child to special day class, while continuing in-home instruction.

77. ***San Diego Unified Sch. Dist.***, 28 IDELR 244 (SEA CA 1998). Parents challenged intensity of speech/language and occupational therapy and also challenged proposed autism services for 3-year-old. Hearing officer found for the parents regarding in-home behavioral therapy, citing district's failure to specify in the IEP what autism services would be provided. Hearing officer also found that proposed services were inappropriate because they did not address the child's individual needs.

78. ***Board of Educ. of the City Sch. Dist. of the City of New York***, 28 IDELR 519 (SEA NY 1998). District proposed placing elementary student with autism in new specialized classroom in a district school. Parents requested placement in a specific private school, in which they had unilaterally enrolled the child. Hearing officer concluded that

district program was appropriate, but review officer found that no evidence was presented on how the program would meet child's individual needs. Parents' request for reimbursement denied, however, because they did not show that private program was appropriate.

79. ***Independent Sch. Dist. No. 281 (Robbinsdale),*** 28 IDELR 370 (SEA MN 1998). Initial dispute over amount of instruction to be provided was settled through mediation. Parents funded additional therapy during that school year. For the following school year, district proposed continuation of ABA program plus classroom participation. Parents challenged program. ALJ determined that student required 40 hours per week of ABA and that district program, which didn't provide that amount, was inappropriate. ALJ also rejected district's contention that home setting was not least restrictive environment.

80. ***Houston Indep. Sch. Dist.***, 28 IDELR 1231 (SEA TX 1998). New York IEP for five year old with autism included preschool program and in-home services. Family moved to Texas, and Texas school district would not honor New York IEP. Services offered were significantly different, and parents unilaterally enrolled child in private school, requesting reimbursement. Although hearing officer found that Texas did not have to implement New York IEP, also found that district denied FAPE by placing child in too restrictive a placement and did not offer in-home training. Parents were denied reimbursement, however, because they failed to meet notice requirements before enrolling student in private program.

81. ***Lexington County Sch. Dist. One,*** 27 IDELR 1182 (SEA SC 1998). Three-year-old had previously received special education services in Connecticut. When parents moved to South Carolina, proposed program was different, and parents rejected the IEP. Parents

began in-home ABA program. Hearing officer determined that district did not have to accept out-of-state IEP or program recommendations. In addition, hearing officer held that proposed IEP provided a FAPE and was consistent with recommendations of expert witnesses.

82. ***Burilovich v. Board of Educ. of the Lincoln Consolidated Schs.,*** 28 IDELR 277 (E.D. Mich. April 24, 1998). Parents agreed to program which was not reduced to written IEP. Parents' request for reimbursement for in-home program was denied. Parents then received written IEP proposal, calling for different program than agreed to orally. Hearing officer found for the parents. Review officer reversed, finding that the written IEP afforded a FAPE. Parents appealed to federal district court, asserting claims under IDEA, Rehabilitation Act, ADA, Section 1983, and state law. Court found no procedural errors under the IDEA, i.e., parents were included in IEP process, and program was based on appropriate evaluation. In addition, court found no violations under other federal or state statutes.

83. ***Clark County Sch. Dist.***, 28 IDELR 804 (SEA NV 1998). Three-year-old student, evaluated by Nevada school district, was categorized as "developmentally delayed" and placed in preschool class. Family moved to California where, after several evaluations, a diagnosis of autism was given. Parents began in-home discrete trial program and requested due process hearing against Nevada district, claiming that district had reason to believe the child might have autism. This resulted, according to parents, in improper identification and placement. Hearing officer determined that district should have known the child was autistic

at the time of evaluation and awarded parents reimbursement for costs of private evaluations after their move and 3 months of in-home therapy.

84. ***Palatine Community Consolidated Sch. Dist. 15***, 29 IDELR 258 (SEA IL 1998). Hearing officer concluded that school district denied 4-year-old with autism a FAPE and ordered reimbursement for in-home program. Review officer upheld decision, finding procedural and substantive errors, but overturning reimbursement for support services beyond regular rate and for costs of 5 independent evaluations.

85. ***Redlands Unified Sch.***, 3 ECLPR ¶ 236 (SEA CA 1998). While agreeing on IEP goals, parents and district could not agree on placement for 3-year-old. Parents wanted in-home discrete trial program, while district offered placement in preschool autism class with home component. Hearing officer determined that proposed placement denied student a FAPE, on both substantive and procedural grounds. Since in-home program was determined appropriate, parents were awarded reimbursement for costs of program.

86. ***Santa Barbara County Office of Educ.***, 3 ECLPR ¶ 248 (SEA CA 1998). Parents challenged past three years' proposed programs for 5-year-old with autism. Child was involved in ABA program at home and in private preschool. Hearing officer found that first year's proposed program was inappropriate, the second denied student a FAPE, and the third was inappropriate. Hearing officer also concluded that parents' program provided educational benefit and met child's individual needs. Parents were awarded reimbursement for program, but for only one of three independent evaluations.

87. ***Prince George's County Pub. Sch.***, 3 ECLPR ¶ 224 (SEA MD 1998). School district funded 40 hours weekly of in-home Lovaas program. District proposed change to

school-based program in anticipation of child's third birthday and transition to preschool. Grandparents agreed to goals but rejected placement, stating that only the Lovaas methodology was appropriate. ALJ determined that district placement was appropriate. Judge also noted that dispute was primarily one of methodology and stated that no evidence had been presented to indicate that child would not progress using methodology other than Lovaas. Also in dispute was "stay put" during pendency of the due process proceedings. ALJ determined that stay-put does not apply to transition from early intervention to preschool services.

88. ***Grapevine-Colleyville Indep. Sch. Dist.***, 28 IDELR 1276 (SEA TX 1998). Parents of 10-year-old with autism requested independent evaluation. District challenged, claiming its evaluation was appropriate. Parents then challenged IEPs, arguing denial of FAPE and requesting new IEP with ABA component and full-day, year-round program. Hearing officer awarded parents reimbursement for medical independent evaluation, finding that district had not investigated possible diagnosis. Hearing officer found that IEPs were inappropriate and not based on complete information and ordered the new IEP to contain a "structured, intensive and systematic" full-day, year-round program with a home component.

89. ***Norwood Pub. Schs.***, 3 ECLPR ¶ 235 (SEA MA 1998). When child with autism reached age three, district proposed a diagnostic placement for eight weeks in district preschool program. Parents rejected placement and began in-home Lovaas program. Hearing officer determined that a formal offer of a new placement had not been made at the end of the diagnostic placement period. Therefore, hearing officer assumed that district would have proposed the child's current placement to continue and concluded that preschool

placement was inappropriate. Parents were awarded reimbursement, as well as prospective funding through the summer.

Mediation in the Individuals with Disabilities Education Act

By Edward Feinberg, Ph.D. and Jonathan Beyer, B.A.

Statutory framework: purpose and origin of IDEA. The Individuals with Disabilities Education Act (IDEA) (Public Law 105-15) is the federal law designed to assure that the 5.8 million[1] American children with special education needs receive a "free appropriate public education." Procedural and substantive requirements of the law affect the manner in which every school district in the United States serves children with special learning needs. With combined federal, state, and local costs of approximately $36 billion per annum,[2] IDEA has had a seismic impact on the design and delivery of the educational services received by more than 10% of American school children.

Elements of IDEA. IDEA-97, the most recent Congressional reauthorization of IDEA, features the following elements:

1) All children with suspected learning problems or disorders must be evaluated by highly trained individuals in the fields in which the disability is suspected. This could include specialists in the fields of learning disabilities, mental retardation, emotional disturbance, speech and language disorders, hearing impairments, visual impairments, and various medical disorders.

2) School districts must assemble "teams" of specialists to determine if a disability exists, according to specific federal criteria, and the types of services needed to assist the child to reach his educational potential. A plan of action, known as an Individual Education Program (IEP), is created by the team.

3) A school district must consider a continuum of placement options based on the needs of the child—from periodic assistance in the classroom by an educational specialist for children with mild disabilities to a separate specialized school for children with significant, complex needs.

4) The financing of services required to meet a child's special education needs must be borne at public expense. While federal funding has constituted about 12% of actual costs, local school districts have been compelled to finance the great majority of special education funding.

The transformation of IDEA by complex problems. Hailed as a landmark change in the conceptualization of educational services,[3] IDEA has enabled tens of thousands of American children to participate in individually tailored programs. It has also spawned thorny questions about the intent, scope, and parameters of the law. Among the issues:

1) How does IDEA differentiate between an "appropriate" versus an "optimal" or "best possible" education? Who determines how such decisions are made?[4]

2) What is the role of professionals who are not part of the school team in determining educational programming? Parents may choose to retain such specialists as psychologists and psychiatrists to provide opinions on services that should be provided by the school. What happens if these individuals recommend a course of action that is different from that which has been deemed appropriate by the school team?

Edward Feinberg, Ph.D. and Jonathan Beyer, B.A. have collaborated on a variety of training and conflict resolution projects. They co-authored an article entitled, "Creating public policy in a climate of clinical indeterminacy: Lovaas as the case example du jour" (Infants and Young Children, Volume 10, Number 3: January 1998) and have presented before national and state organizations. Dr. Feinberg is the director of a multi-agency early intervention program in Maryland. Mr. Beyer, who will receive his Juris Doctor degree from the Georgetown University Law Center in 1999, is a health policy analyst who has written on managed care in both pediatrics and geriatrics. They can be reached at 301-309-3799; fax 301-309-6312.

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3) How is a school district to provide for the specialized needs of some children who require services that are well beyond the costs of typical per-child expenditures while also providing reasonable educational services to all other children residing in the district?

Resolution of conflicts under IDEA. IDEA provides recourse to parents who are dissatisfied with the recommendations of the school district through a formal administrative hearing process. However, the hearing process has been criticized as time-consuming, adversarial and expensive.[5] IDEA-97 requires states to develop alternative dispute resolution processes. While many *states* have developed mediation systems, this is the first time that *federal* regulations have mandated mediation.[6] Parents can still choose formal hearings to resolve disputes; however, IDEA-97 requires school districts to discuss the benefits of mediation to all parents who file an administrative hearing request.

Recent sources of disputes in IDEA. The uncertainty of whether methodologies or therapies that are undergoing the lengthy process of potential validation should be included within the scope of IDEA has proven a particularly vexing source of conflict. Experimental research can produce a variety of educational methodologies that promise positive developmental changes for sub-populations of children with disabilities. Longitudinal investigation eventually discredits some of these theories. However, until there is conclusive long-term follow-up data, supporters of such methodologies typically maintain that IDEA mandates the provision of the new approaches to children who might benefit from them.

Emergence of disputes around autism methodologies. During the past several years, the issue of whether a new methodology for children with autism should be held within the scope of the IDEA entitlement has dominated administrative hearings around the country. Affecting approximately one out of every 750 children, autism is characterized by extreme social and communicative withdrawal. More than 90% of adults with autism currently reside in institutional or supervised care settings.[7]

Dr. O. Ivaar Lovaas and colleagues published articles in 1987 and 1993 that stunned the disabilities community by concluding that autism could be effectively treated through a system of intensive behavioral training.[8] Intervention, which started at about three years of age, required adherence to a strict regimen of daily intervention. Through two to three years of one-on-one training for 40 hours per week by specialized behavioral therapists, Lovaas reported that 50% of his sample of 19 children essentially displayed no symptoms of autism at the end of the experimental period. Five years later the experimental group was considered "indistinguishable" from their nondisabled peers.

While academicians questioned methodology, sample size, and generalizability of results,[9] a Lovaas movement developed that attracted a minority of professionals and an ever-growing cadre of families. These families formed coalitions to advocate the incorporation of Lovaas methodology into the IDEA entitlement. Costs for this labor-intensive form of intervention, however, average about $40,000 per child per year as compared with $5,000 to $8,000 per child for conventional special education intervention at the preschool level. Consequently, school districts have been reluctant to finance this methodology. They maintain that the efficacy of intervention remains uncertain and that the intervention exceeds the scope of IDEA. Financially beleaguered school districts further contend that they cannot afford to support this expensive service; yet, private third-party payers and Medical Assistance generally refuse to consider such an intervention among the responsibilities of medical or health systems.

Lovaas disputes. Lovaas disputes have proven the dominant source of conflict among school districts, and parents in a growing number of states. Myrna Mandlawitz, Director of Government Relations for the National Association of State Directors of Special Education, has compiled an ever-expanding analysis of cases that have proceeded through federal and state level administrative and judicial processes. While the emerging decisions from these cases have produced no clear pattern of resolution, parents seeking payment for Lovaas intervention from school districts frequently are successful when those districts violate the procedural regulations of IDEA. There has been a polarization between Lovaas advocates and school districts which has made nonadversarial conflict resolution a path not often pursued.

Lovaas mediation: a case study. In July 1997, the Director of Special Education from a school district in Colorado contacted the authors of this article, who had previously written and lectured about the Lovaas controversy. The Director requested assistance in a case in which a family had obtained Lovaas intervention through a private organization from California. This organization had trained several individuals in the community to provide intensive behavioral intervention. The three-year-old child who is the subject of the dispute had allegedly begun to demonstrate positive developmental changes; but the training, supervision, and daily therapy costs were expected to exceed $30,000 per annum.

Based on the child's apparent developmental gains, the family considered the intervention an appropriate service under IDEA and therefore expected the school district to cover all costs. Conversely, the school district contended that they had constructed an appropriate program which included special education, speech therapy, occupational therapy, and consultation by a behavioral specialist.

The advocate who accompanied the family to mediation was an employee of the Lovaas organization and the parent

of a child with autism. School system personnel were joined by the attorney who is retained by the district exclusively for matters pertaining to special education law.

Defining interests. Rather than fostering discussion on the needs of all children with autism or whether Lovaas is within the scope of IDEA, the authors began the session by asking the parents to describe their child. Eager to discuss their child's history and present functioning, the family movingly presented their recollection of the shock at learning of their child's diagnosis and prognosis as well as their enjoyment of particular personality traits. School district personnel began to empathize with the family. They were able to imagine undertaking a similar direction if they had received such information regarding their own children. They could also recognize that the family, busily engaged in researching various methodological options for young children with autism, was understandably unconcerned with the relatively abstract issue of the scope of federal entitlements.

Creating consensus. Since the family and school-based clinicians involved in the mediation were already familiar with the child's needs and learning styles, the mediators asked that the initial discussion focus on the specific issues pertaining to the child. Each area of developmental functioning was then carefully reviewed, enabling the school therapists to integrate their insights with those of the family regarding the child's day-to-day functioning. As consensus and common ground were fostered between the school-based personnel and family, the discussion shifted away from esoteric issues of entitlements to the specific needs of the child.

The family and school-based clinicians then prioritized developmental areas to be targeted for intervention. Areas of discussion concerned how developmental changes would be operationally defined and observed, as well as under which circumstances changes could be expected, and the variety of locations in which the changes would occur. Outcome statements that could be quantified and easily observed replaced the kind of vague assertions (such as "child will interact in an increasingly socially adaptive manner with a variety of disabled and nondisabled peers") that often appear in Individual Education Programs.

Creating an action plan. The mediators then encouraged the family and clinicians to review each goal and to define by frequency, intensity, and type the specific service that would be needed to maximize the likelihood of achieving the goal. Emphasis remained on integrating the particular learning styles and needs of this child with the goals that had been defined by the team. All parties demonstrated a clear desire to build on the good will that had been generated through the first 12 hours of discussion. The spirit of consensus created in the earlier phases of mediation continued to develop as the session continued.

The action plan that ultimately emerged contained more hours of direct service than the school district had originally offered but nonetheless significantly departed from the classic Lovaas method of intervention. Most importantly, however, the family and the clinicians were pleased with the outcome and concluded that they had designed a program that would benefit the child's development.

Fostering a climate of negotiation and mediation under IDEA. While IDEA-97 formally endorses mediation as a preferred method of conflict resolution over administrative hearings, school district employees and family advocates are generally unaccustomed to this form of conflict resolution. Both sides are accustomed to adversarial adjudicative processes and therefore tend to be highly positional. Even though Individual Education Programs theoretically are designed to stress individual needs, school districts frequently are concerned with the precedential implications of offering a particularly unique program of intervention to a single child. Alternatively, advocates often find school districts to be bureaucratically impenetrable. They complain that there are too many school system employees at IEP meetings and that parents encounter professionals who speak in an educational jargon having little apparent relationship to what they have observed of their own children.

School district employees and advocates need to become proficient in the process of negotiation and alternative dispute resolution strategies for the IDEA-97 recommendations concerning conflict resolution to succeed. As special education regulations encourage greater family participation in all phases of decisionmaking and as new methodologies for various disabilities are discovered, such skills will prove even more essential to all parties in determining appropriate educational decisions for each child with special needs.

Endnotes

[1] *Nineteenth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*, U.S. Department of Education, 1997. (Data for the 1995-1996 school year, the last year for which complete information is available.)

[2] *Ibid.* [Table I-23 provides information on state-by-state costs as well as federal allocations].

[3] Barbara Hanft, M.A., O.T.R., F.A.O.T.A. (former lobbyist with the American Occupational Therapy Association), personal communication, February 1998.

[4] *Hendrick Hudson District Board of Education v. Rowley*, 458 US 176, 192 (1981).

[5] Gittler, J. and Hurth, J., "Conflict Management in Early Intervenuon: Problem-Solving Negotiation," *Infants and Young Children*, 1998;11(1).

[6] Individuals with Disabilities Education Act Amendments of 1997, Part C—Infants and Toddlers with Disabilities, Pub. L. 105-17, 111 Stat. 37, 106-123, 631-645 (1997).

[7]Cooper, E.F., "Autism: Background Information and Federal Research Funding Levels," Congressional Research Service of the Library of Congress, August 2, 1996, Washington, D.C.

[8]Lovaas, O.I., "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children" *Journal of Consulting and Clinical Psychology*, 1987;55(1):3-9. McEachlin, J.J., Smith, T., Lovaas, O.I., "Long-Term Outcome for Children with Autism Who Received Early Intensive Behavioral Treatment," *American Journal of Mental Retardation*, 1993; 97(4); 359-372.

[9]Schopler, E., Short, A., Mesibov, G., "Relation Of Behavioral Treatment to 'Normal Functioning': Comments on Lovaas," *Journal of Consulting and Clinical Psychology* 1989, 57;162-164 ☒

Glossary of Terms

Autism Society of America

Glossary of Terms

The following list of terms and acronyms has been adapted, with permission, from the "List of Terms" (at http://www.autism-society.org/packages/glossary.html, last updated 12/5/98), developed and maintained by Ben Dorman & Jennifer Lefever for the Web site of the Autism Society of America.[1]

AAP: American Academy of Pediatrics

ABA: Applied Behavior Analysis

ADA: Americans with Disabilities Act of 1990

ADD: Administration of Developmental Disabilities

ADD: Attention Deficit Disorder

AD/HD: Attention-Deficit/Hyperactivity Disorder

AIT: Auditory Integration Training (sometimes called AT for Auditory Training)

AMA: American Medical Association

ARC: Association of Retarded Citizens

ARI: Autism Research Institute

ASA: Autism Society of America

ASAF: Autism Society of America Foundation formed in 1996 to advance research that will yield new information about autism

ASD: Autism Spectrum Disorders

ATP: Autism Tissue Program

Aversive: Controversial behavior reduction approach

Behavior Modification: Techniques used to change behavior through reinforcement

BD: Behavioral Disorder

CAN: Cure Autism Now

CAP: Client Assistance Program administered by the Office of Special Education & Rehabilitative Services; provides information and assistance to individuals seeking services under the Rehabilitation Act

CARS: Childhood Autism Rating Scale (diagnostic tool)

CDC: Center for Disease Control and Prevention

CEC: Council for Exceptional Children

CHAT: Checklist for Autism in Toddlers (diagnostic tool)

Continuum: Used to describe a full range

DAN!: Defeat Autism Now!

DD: Developmental Disabilities

DEC: Division for Early Childhood of the Council for Exceptional Children

DMG: Dimethylglycine, a food substance resembling a vitamin

DSM: *Diagnostic Statistical Manual*, produced by the American Psychiatric Association now in its fourth edition (1994)

DTT: Discrete Trial Teaching

Echolalia: The repetition or parroting of words or phrases

ED: Emotional Disorder

ED: Education Department

EDGAR: Education Department General Administrative Regulations

EHA: Education of all Handicapped Children Act (now named Individuals with Disabilities Education Act (IDEA)), reauthorized and amended in June 1997

Epidemiology: the distribution of diseases or disorders through the population

ERIC: Educational Resources Information Center, a computer database of educational information run by the Council for Exceptional Children

ESY: Extended School Year

Etiology: the cause of a disorder

FAPE: Free Appropriate Public Education

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1 Autism Society of America
7910 Woodmont Ave, Suite 300
Bethesda, MD 20814-3015
(800)-3AUTISM or (301)-657-0881
Fax: (301)-657-0869
URL: http://www.autism-society.org/

FERPA: Family Education Rights and Privacy Act: Governs the privacy of a student's school records

FC: Facilitated Communication

Fragile X: Refers to the X chromosome; a genetic condition affecting cognitive, physical and sensory development

HCBS: Home and Community Based Services

I&R: Information and Referral service

IBI: Intensive Behavioral Intervention

IDEA: Individuals with Disabilities Education Act of 1990 (P.L. 102-119), amended by the Individuals with Disabilities Education Amendments Act of 1997. (Previously called EHA-see above)

IEP: Individualized Education Program — document which describes the agreed upon services to be provided by the school to a child with a disability (ages 3-21)

IFSP: Individualized Family Service Plan — similar to an IEP (ages birth-3)

IHP: Individualized Habilitation Program — Often similar to an IEP for adults with disabilities

IPP: Individual Program Plan

IRCA: Indiana Resource Center for Autism

ITP: Individual Transition Plan (ages 16-21)

Inclusion: Placement of a child with a disability with his non-disabled peers

JADD: Journal of Autism and Developmental Disorders

Landau-Kleffner Syndrome (LKS): A rare disorder marked by sudden loss of language between the ages of 3-7, after a period of normal development. Individuals with LKS are also characterized by an abnormal EEG.

LD: Learning Disability

LEA: Local Education Agency

LRE: Least Restrictive Environment

MAAP: A Newsletter for Families of More Advanced Individuals with Autism, Asperger's Syndrome, and Pervasive Developmental Disorders

Mainstreaming: Placement of a child in a classroom with non-disabled peers versus a separate classroom

MH: Mental Health

MR: Mental Retardation

NAAR: National Alliance for Autism Research

NAPAS: National Association of Protection & Advocacy Systems

NASDSE: National Association of State Directors Of Special Education

NBD: Neurobiological Disorders

NECTAS: National Early Childhood Technical Assistance System

NICHCY: National Information Center for Children and Youth with Disabilities

NICHD: National Institute of Child Health and Human Development

NIDCD: National Institute of Deafness and Other Communication Disorders

NIH: National Institutes of Health

NIMH: National Institutes of Mental Health

NINDS: National Institute of Neurological Disorders and Stroke

NSAC: National Society for Autistic Children, previous name of the Autism Society of America

OCD: Obsessive Compulsive Disorder

OCR: Office of Civil Rights

OSEP: Office of Special Education Programs

OSERS: Office of Special Education and Rehabilitative Services

OT: Occupational Therapy

P&A: Protection & Advocacy Agency: Designed to protect Individuals with disabilities, every state has one

Part B: Part B of IDEA, addresses special education services, ages three through twenty-one

Part C: Part C of IDEA — addresses early intervention services for children age birth to 3. This was formerly Part H of IDEA until July 1, 1998, when the provisions of the 1997 Amendments came into force

PASS: Plan for Achieving Self Support: employment program for adults with disabilities

PTI: Parent Training Information Center

Perseveration: The practice of repeating a behavior over and over or the habit of pursuing a topic relentlessly

PDD: Pervasive Developmental Disorder

PDDNOS: Pervasive Developmental Disorder Not Otherwise Specified

P.L. 94-142: Public Law 94-142: Education for All Handicapped Children Act — amended in 1990 to become the IDEA

PT: Physical Therapy

Respite: Periodic and temporary care provided for parents to have time away from children with special needs

Rett's Disorder: A progressive disorder in girls marked by a period of normal development and then loss of previously acquired skills.

SEA: State Education Agency

SED: Serious Emotional Disorder

SI: Speech Impairment

SI: Sensory Integration

SIB: Self-Injurious Behavior

SLP: Speech-Language Pathologist

SSA: Social Security Administration

Stimming: The informal term for self-stimulation

SSI: Supplemental Security Income

SSDI: Social Security Disability Insurance

STOMP: Specialized Training of Military Personnel

TEACCH: The Division for the Treatment and Education of Autistic and Related Communication Handicapped Children, North Carolina organization

UAP: University Affiliated Program

VOC-ED: Vocational Education

National Early Childhood Technical Assistance System
137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
(919) 962-2001 (voice) ❖ (919) 962-8300 (TDD)
(919) 966-7463 (fax)
E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/